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**Infertility: A Quantitative Report of Clinical Psychologists'
Therapeutic Contact with Sub-Fertility Clients, and a Qualitative
Analysis of the Experience of these Clients' and Their Subsequent
Psychological Adjustment, Following the Discontinuation of In Vitro
Fertilisation Treatment.**

A thesis submitted in partial fulfilment of the requirements of the Open University for
the degree of Doctor in Clinical Psychology

July 1998

**SALOMONS
CANTERBURY CHRIST CHURCH COLLEGE**

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Confidentiality

The information contained within this investigation has been written-up to preserve the anonymity of all those who took part. Any characteristics that could have potentially led to the identification of individuals have been omitted.

Abstract

Objectives:- The aims of this investigation were two-fold. First, within the literature no firm conclusions have been drawn about the nature of the psychological and therapeutic needs of individuals with fertility problems. The first section of this investigation, therefore, attempted to explore in more depth the interaction between Clinical Psychologists and the infertile population.

Second, research examining the psychology of receiving treatment for infertility (namely, In Vitro Fertilisation - IVF) has largely overlooked the experiences of those for whom treatment has been unsuccessful and a decision to stop has been made. The aim of the second section of the investigation was therefore, to gain a more detailed understanding of the experience of individuals stopping IVF, and to look closely at their adjustment and coping.

Design:-

Section One - A survey design was employed.

Section Two - A qualitative research paradigm using a grounded theory methodology was employed.

Method:-

Section One - A survey instrument was developed to explore Clinical Psychologists therapeutic contact with persons with fertility problems. Of a total of 1000 questionnaires distributed, a response rate of 43.6 per cent was achieved.

Section Two - Eleven participants were recruited from a population of patients who had discontinued unsuccessful IVF treatment. Face-to-face interviews were conducted, exploring participants' feelings and experiences across three areas: (1) their experience of the IVF treatment process; (2) their decision to stop treatment; (3) their lives 'post decision'.

Results:-

Section One - only a small proportion of the sample were found to be working with individuals with fertility problems. Female clients were more likely to have been seen therapeutically, with those undergoing infertility treatment during therapy essentially receiving the most Clinical Psychology service resources. Clients were unlikely to be referred to services for issues related to their infertility, whilst the primary therapeutic task was often identified as dealing with issues of infertility.

Section Two - Transcripts of participants' interviews were analysed using aspects of grounded theory methodology. Five themes were identified as unifying the data.

Conclusions and Implications:- The quantitative survey findings suggest that at present, services may not be fully addressing the therapeutic needs of the infertile population. Specific difficulties were found to exist at the point of initial referral. Suggestions are made for improving the service delivery to this client group.

A tentative theoretical framework was developed to explain the experience and adjustment of individuals discontinuing IVF treatment. This preliminary process model suggests that certain psychological and social factors exist which have the potential to lead to a greater or lesser degree of adaptation for individuals (the effects of these factors are mediated by a core process within the individual, namely their belief system). The implications of this model for preventative and therapeutic interventions are discussed, both in relation to services provided by Clinical Psychologists and for other professionals working in specialist infertility services.

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1. Introduction

1.1 Outline

Throughout history men and women have struggled, largely in silence, to bear the pain and cope with the tragedy of being childless. Until recently, medical interventions were not available to provide those diagnosed as infertile with a chance to become biological parents. Thus individuals had little choice but to accept their situation. Whilst currently the outcome for individuals experiencing problems of a reproductive nature is less bleak, in that technological advances now provide some hope for conception, the rate of treatment success is low (Human Fertilisation & Embryology Authority - HFEA, 1997). Many individuals continue, therefore, to feel let down by their own perceived inadequacies and failure.

The process of treatment for infertility has often been likened to that of a roller-coaster (Read, 1995; Hunter, 1994), with the expectation that it will at times be a traumatic and distressing ride; depending on outcome, it may also be a source of great happiness or despair for the couple concerned (Callan & Hennessey, 1989). Although In Vitro Fertilisation (IVF) is only one of a number of treatments available to the infertile, it is clearly regarded from a medical perspective as 'punctuating the end of the treatment line', with couples similarly viewing it as their 'last chance' for a biological child (Litt, Tennen, Affleck & Klock, 1992).

Failure for individuals at some stage within an IVF treatment cycle is almost inevitable, even though at the outset, a large proportion will significantly underestimate the likelihood that this will happen to them (Johnston, Shaw & Bird, 1987). Couples who are unsuccessful often go on to receive further treatment and it has been suggested

that, because they continue to hope for a successful outcome they are not as yet ready to face the reality and personal meaning of being childless (Dennerstein & Morse, 1988). Arguably therefore, only when an individual is prepared to 'let go' of their hoped for success and can terminate treatment which is unsuccessful, are they then able to begin the process of adjustment and acceptance of their infertility and childlessness.

It is an inescapable fact that terminating IVF treatment is an issue which has to be faced by many individuals at some stage within their 'treatment career'. Although in some instances clinicians, rather than the individuals themselves, make the decision to stop, decisions of this kind are frequently being made within services. Given this then, it is surprising that little is actually known about the psychological impact of this process upon the infertile individual. It seems pertinent, therefore, to ask questions about how individuals experience their infertility and the decision to discontinue treatment and, in particular, how they cope and adjust to a life after treatment, in which biological children will play no part.

Research to date with the infertile has, as yet, not concerned itself with the experience of individuals who 'give up' IVF treatment. Therefore, this review will concentrate primarily upon presenting information about the psychological processes which would seem of relevance to this group, and to the process of their adjustment.

Initially, to establish a context for this current enquiry a detailed consideration of the individuals for whom infertility is an issue, and the medical and psychological processes involved in IVF treatment will be presented.

1.2 The Infertile Population

Infertility, 'the inability to achieve a pregnancy after one year of regular intercourse without the use of contraception' (Edelmann & Connolly, 1994, p. 89), is commonly known to affect a large percentage of people of child-bearing age. Whilst the archaic and derisive descriptions previously used to depict the infertile are seldom now articulated, society generally remains ignorant of the extent of the problem and thus the stigma attached to being childless is maintained.

Whilst it is estimated that about 15 per cent of couples of child-bearing age experience problems with fertility (currently approximately 600,000 couples in Britain; Winston, 1996), there is no real way of knowing the true extent of the problem as not everyone affected seeks medical help. However, it is possible to say that at least one couple in every six will seek some form of specialist help in their attempt to become biological parents (Hunter, 1995; Hull, Glazener, Kelly, Conway, Foster, Hinton, Coulson, Lambert, Watt & Desai, 1985).

Labelling infertility as a 'problem of the 90s' (Benson & Robinson-Walsh, 1998), suggests that the problem is indeed escalating. However, it is unclear to what extent this is just a consequence of the 'consumer culture' in which we live, with more individuals now seeking a medical solution to their childlessness; are individuals just simply more vocal, and less likely to be resigned to the facts of their infertility today? Attitudes have undoubtedly changed though, and with the advent of more sophisticated treatments, 'going public' is now undeniably more desirable and beneficial for the infertile. Nevertheless, admitting one's infertility, whilst perhaps now more socially acceptable, is hardly an envied position.

Reasons for infertility are varied and medically complex. Historically, problems were thought to lie with women (Stonehouse, 1994), whereas in reality, cases of infertility are equally due to female problems, problems with male sperm, and joint problems (Benson & Robinson-Walsh, 1998). There is little evidence in support of a psychogenic basis to infertility, and even though some infertility experts (Sarrell & DeCherney, 1985; Mai, Munday & Rump, 1972) continue to believe the proposition that underlying psychological conflicts play a role in infertility, particularly where no organic explanation can be found, this is not the majority view (Dennerstein & Morse, 1988).

Problems are usually only identified when a couple begin to test their fertility by trying for a family. Some have suggested that the change in the position of women within society may have contributed in part to a decrease in their fertility. Women are increasingly recognised as having more to contribute than merely being 'the bearers of children', and now many pursue careers before taking time out to raise a family. However, couples who decide to start child-bearing later in life risk leaving already existing problems untreated, which may affect their fertility in the long term and in some cases irredeemably.

By choosing to delay conception beyond what is medically recognised as the period of natural fertility, many women experience problems with fertility: poorer egg quality, lower conception rates and a greater risk of miscarriage being the most common. In addition to this, measures to tackle infertility such as IVF, become less successful as a couple grow older, and for women, treatment will not be administered beyond a certain age. Other reasons cited for the possible increasing incidence of infertility include the

prolonged use of female oral contraceptives, increased exposure to drugs and environmental pollutants, and venereal disease (Stanway, 1984).

1.3 'The Need to Conceive' - Choices, Control and the Social Context

To an extent, most individuals have some idea about the direction they would wish their life to follow, as well as having the autonomy to change or choose a different path when obstacles prevent the realisation of their goals. The opportunity to make choices and control facets of life is therefore integral to the adult phase of life, with choices concerning marriage, career, living arrangements, child bearing and raising, being just some of the decisions over which adults anticipate having a significant degree of control.

However, encountering problems with one's fertility threatens these fundamental assumptions. Individuals who are infertile lose the power to control their own life, their health and place within society (Bright, 1996), with their lives often turning out to be very different to what they had hoped or planned for. Interestingly, individuals (like those with fertility problems) who perceive their locus of control to be externally rather than internally oriented, have been found to cope less well generally with health problems (Strickland, 1978).

The pressure to procreate originates from both external as well as internal sources. According to Callan (1986), individuals are compelled to want children in order to achieve fulfilment and a purpose to their life, as well as satisfying an inherent biological need (contributing to the continuity of human existence). However, it is also recognised that there is an immense pressure to have children to conform to the

perceived societal norm of the family unit (Benson & Robinson-Walsh, 1998). This is despite the fact that the normative family structure of husband, wife and 2.2 children, seldom now exists.

Society implicitly expects individuals to want to have children, hence women have been labelled as 'normal' if they achieve pregnancy easily, 'fanatical' if they cannot, and less than 'real women' when they choose not to (Stanworth, 1987). Accordingly, Unruh and McGrath (1985) suggest that because women have been socialised to value themselves primarily through their childbearing roles, and in some respects not to look for satisfaction beyond their role as mothers, the experience of infertility throws into question their feelings of self worth and self esteem.

1.4 In Vitro Fertilisation (IVF) Treatment - the Technicalities

Achieving a pregnancy and successfully bearing a child through IVF treatment (so called 'test-tube' babies) was first made possible in the late seventies (Stephoe, Edwards & Purdy, 1980). This treatment was originally only developed to help women with blocked fallopian tubes, when reconstructive surgery had failed or was not possible. But nowadays it is used additionally to treat problems of male infertility, and to help couples where the cause of their infertility is 'unexplained'. IVF cannot, however, be used to help women whose ovaries are unable to produce eggs, or when the uterus is damaged or congenitally deformed. In these instances, the only potentially viable options available to couples are to either use donor eggs or to recruit a 'surrogate' (Winston, 1996), both of which raise complex and difficult moral and social dilemmas for couples.

Essentially, an IVF treatment cycle involves fertilising eggs extracted from the female patient outside of the body, placing any embryo which is fertilised back into the uterus, and waiting to see if it implants and grows into a baby. Initially, fertility drugs are given to stimulate egg production. Eggs are then collected under a local anaesthetic and mixed 'in vitro' with sperm from the male partner. Fertilisation rarely occurs in all the eggs collected, but those embryos which are fertilised are cultured and grown and then transferred back to the uterus.

In order to avoid the known risks attached to multiple births (Harvey & Bryan, 1991), for the mother, the potential pregnancy, and any child born, guidelines are provided by the HFEA stipulating the number of embryos which it is deemed safe to return; most clinics operate a policy of transferring just two embryos (HFEA, 1997).

Once embryo transfer has occurred nearly all patients fantasise that they are pregnant (Winston, 1996), but it is not until 10 to 14 days later that their true status can be ascertained. Unfortunately, figures for 1995 indicated that the average live birth rate per stimulated IVF treatment cycle was only 15.5 per cent, with success correspondingly rising to 17.2 per cent for women aged less than 25, and falling to 13.1 per cent in women 35 to 39 years of age (HFEA, 1997).

In 1993, intracytoplasmic sperm injection (ICSI), a variation on the traditional IVF method, was introduced to combat the problem of low male sperm counts and to thus increase the likelihood of success for some patients. This technique involves selecting a single, good quality sperm, injecting it directly into the inner cellular structure of the egg, and then transferring in back into the uterus. Whilst the live birth rate for ICSI

treatment is broadly similar to that of standard IVF (HFEA, 1997), success rates for both do seem to differ across treatment sites.

IVF treatment is subject to rigorous control by a statutory licensing authority which, amongst its many regulatory and monitoring roles, licenses clinics offering IVF and other treatments for infertility (Department of Health & Social Security, 1987). At times though, there have been concerns expressed regarding the rate of development of IVF technology, and in particular how this has outpaced clinicians' and researchers' efforts to anticipate and explore its social consequences (Braverman & English, 1992). Those in opposition to the artificiality of conception following IVF, have argued that 'the unitive and procreative aspects of sexual intercourse should not be separated' (Department of Health & Social Security, 1984, p. 31). These individuals are, however, usually speaking from their privileged position as parents, and as such are unlikely to fully appreciate the devastating consequences of infertility, or have the ability to empathise with those less fortunate than themselves.

1.5 IVF Couples - an Exclusive Club?

Findings from epidemiological research have indicated that nearly a third of all infertile women do, in fact, choose not to seek treatment to overcome their fertility problems (Templeton, Fraser & Thompson, 1990). Whilst the reasons for this are largely unknown, studies have estimated that only five per cent of the world's married population actually choose to remain voluntarily childless (Veevers, 1980).

The qualities of couples entering IVF treatment programmes have been extensively studied. As IVF makes many demands upon its recipients, both emotionally and

financially, those who agree to undertake it have to be highly motivated (Hunter, 1994). Whilst those choosing not to pursue it have been described as poorly motivated and less well adjusted (Chan, O'Hoy, Wong, So, Ho & Tsoi, 1989). However, the implication here, that the only way to cope successfully with one's infertility is through seeking a medical solution is not accepted by some couples (Templeton et al., 1990). Arguably, this way of conceptualising infertility denies the value to be gained from other ways of coping and in some instances may compound distress for individuals for whom treatment is unsuccessful and has to be discontinued.

There are some who believe that certain couples select themselves out of the infertility treatment process prior to any medical intervention. According to Cook, Parson, Mason & Golombok (1989), only couples with a strong marital relationship ever reach the stage of receiving IVF. Couples undergoing IVF are similarly found to score higher than those receiving other less intense fertility procedures on psychometric measures of ambitiousness, creativity and independence (Given, Jones & McMillen, 1985 cited in Dennerstein & Morse, 1988).

Disruptions to lifestyle during an IVF treatment cycle is inevitable. Couples are required to reorganise their daily domestic routines to allow them to make frequent hospital visits and to administer regular medications. Treatment is known to be invasive, and in some respects may be regarded as disempowering by patients; clinicians are intervening to medicalise the most intimate part of a couple's relationships, making major decisions about when and how to treat, and in some cases when to stop. Furthermore, as infertility treatment has become an increasingly male-controlled aspect of healthcare, concerns have been expressed that women are

relinquishing the right to control their own health, becoming merely passive recipients of treatment, and once again allowing themselves to be dominated by men (Benson & Robinson-Walsh, 1998).

The financial expense involved in administering IVF potentially limits the extent of its availability. Patients who are fortunate enough to receive National Health Service (NHS) funded treatments, frequently endure a lengthy, protracted waiting period, with treatment usually limited to a specified number of cycles. Because of this, individuals are often forced prematurely to face the distressing decision of whether to discontinue treatment or not. For those living in a catchment area served by an Authority which does not regard infertility as a sufficiently serious medical condition, private treatment is therefore the only option. Self-funding is usually not a financially feasible proposition, and whilst most clinics are managed on a 'not for profit' basis, the lure of private patients may in fact lead some unscrupulous practitioners to treat unsuitable candidates.

1.6 Models of Stress and Coping

Much is known about the strategies that infertile individuals employ to cope with their infertility and its treatment (Callan & Hennessey, 1989; Litt et al., 1992). Whilst these theories have not as yet been considered when thinking about adjustment and coping following decisions to terminate treatment, they may provide a useful framework for exploration in this area.

Coping refers to the action taken by individuals as a way of protecting their overall level of well-being in the face of life stresses (Callan & Hennessey, 1989). According to cognitive theorists, coping occurs under conditions of psychological stress, when the demands of the situation exceed the individual's existing personal resources.

Coping strategies (the cognitive and behavioural efforts used by individuals to deal with stress) are thus employed in an attempt to master, tolerate, or reduce the presenting 'stressors' (Lazarus & Folkman, 1984).

Not everyone experiences the same situations as stressful. The extent to which a situation is experienced in this way depends in part upon the individual's cognitive appraisal of it. Life changes and circumstances which are perceived by the individual as uncontrollable and a threat to their well-being, such as, losses or problems with fertility, often lead to feelings of distress for the individual, and are commonly found to be precipitants of problems with mental health, for example, depression (Hunter, 1994; Brown & Harris, 1978). Furthermore, it is recognised that the resources available to an individual within their psychosocial environment can enhance coping ability, with intrapersonal and interpersonal resources seemingly acting as a buffer to the potentially harmful consequences of the 'stressor'.

Different people have different ways of expressing and managing their distress. The more varied and flexible the repertoire of coping skills are, the more protected the individual is said to be when faced with personal crises (Pearlin & Schooler, 1978). Within the cognitive framework outlined, three types of coping strategies are believed to be employed by infertile individuals; appraisal-focused coping, emotion-focused coping and problem-focused coping (Callan & Hennessey, 1989).

- *Appraisal-focused coping:* here strategies are employed by the infertile individual in an attempt to understand and find a pattern of meaning to their crisis. Individuals may, for example, attempt to redefine their problem by remembering

that things could be worse, or engaging in behaviours to keep themselves busy, using strategies of avoidance and denial to gain temporary relief from the problem.

- *Problem-focused coping*: here the individual consciously confronts the reality of their crisis, making attempts to establish solutions or discover viable alternatives. This may involve actively gathering information from which a plan of action can be drawn; taking steps to be more objective and devising new life plans; or looking for a positive side to the situation and searching for alternative rewards, for example, adoption.
- *Emotion-focused coping*: these strategies are used by individuals to regulate and deal with the emotional distress generated by the fertility crisis (Hynes, Callan, Terry & Gallois, 1992). Here, infertile women may cope with their feelings of jealousy towards pregnant friends by avoiding likely social encounters, or conversely, they may intentionally expose themselves to these situations. More maladaptive ways of coping here involve forms of 'acting out' (Moos & Schaefer, 1986), where individuals may engage in behaviours such as extramarital affairs, drug and alcohol misuse, or use humour as a way of concealing and denying their underlying feelings (Callan & Hennessey, 1989).

In practice, some ways of coping are unquestionably more functional and adaptive than others. Individuals will often adopt different strategies at different times in their lives, drawing upon previously successful models of coping. However, these may or may not be suitable for the crisis they currently face. In the case of the infertile individual this may be the difference between being hindered or being helped towards adjustment.

Infertile women have been found to experience higher levels of well-being, including enhanced feelings of self confidence and self esteem, and lowered levels of depression, when they use problem focused strategies to help them cope following failed IVF treatment (Hynes et al., 1992). In contrast, poorer mental health outcomes appear to be associated with the more emotion-focused styles of coping, such as seeking social support and avoidance, which confirms the theoretical stance of Folkman, Lazarus, Gruen and DeLongis' (1986).

Litt et al. (1992) have also found that being in a satisfying relationship with a partner, generally, does not act to buffer individuals from the distress of their infertility. Perceiving oneself to be in control of the situation does, however, appear to serve a protective function (Reading, Chang, Kerin, 1989), whilst 'unexplained' infertility makes one more vulnerable and at risk (Berger, 1977).

1.7 Models of Loss and Grief

The process of discovery and acceptance of one's infertility has often been described as a form of bereavement, in which couples or individuals mourn the loss of their longed for child, and grieve for the loss of the expected parenting role (Singer & Hunter, 1997; Bright, 1996).

Within models of grief, individuals are assumed to reach an eventual state of acceptance and resolution of their loss by progressing through a series of stages; namely shock, disbelief and denial, anger, bargaining, and depression or withdrawal (Kubler-Ross, 1970). Whilst individuals faced with infertility do experience a diverse range of emotions, similar in many respects to those of the bereaved, their emotional

response rather than being a time bound sequential process ending in acceptance and closure, is according to some, more akin to a model of 'chronic sorrow' (Unruh & McGrath, 1985). Here feelings of sadness and sorrow for what is missing and for what remains, are paramount, re-emerging continuously throughout the life cycle. Evidence for this conceptual framework emanates from studies which have found that infertile women often experience cyclical hope and despair, corresponding to the phases within their menstrual cycles (Dennerstein & Morse, 1988). Similarly, couples often experience recurring periods of distress triggered by the anniversaries of their treatment failure (Baram, Tourtelot, Muechler & Haung, 1988).

Another model which is clearly useful in considering the human experience of infertility is Worden's (1982) model of bereavement, in which it is assumed that individuals must accomplish various 'tasks' of mourning if they are to reach a satisfactory conclusion following their loss. Within this model, grief, is said to encompass both losses of person and of significant entities or relationships, and is therefore, particularly applicable to infertility (Bright, 1996). According to Worden the four tasks of mourning to be achieved are:

- i) accepting the reality of the loss
- ii) experiencing the pain of the loss
- iii) adjusting to an environment in which the lost object is no longer present
- iv) withdrawing emotional energy away from the loss

Although to successfully resolve one's grief the four tasks need not be accomplished in any specific order, each must be 'worked through' and in some instances help is required to facilitate this process (Worden, 1985). Couples facing the loss of their

fertility may experience difficulties at various stages within this process, particularly because participation in a demanding treatment process such as IVF is deemed incompatible with a rapid acceptance of one's infertility (Woods, Olshansky & Draye, 1991).

Infertile couples are not a homogenous group, and as such they respond differently to failure and loss within an IVF treatment cycle. Worden (1985) suggests several factors which contribute to an individual's experience of grief, stating,

'the personal experience of loss is a multidetermined phenomenon [in which] no single factor ... can explain the variance in experience' (Worden, 1985, p.474).

Worden believed that knowledge of these 'determinants of the grief response' could be useful in identifying those at risk from a poor resolution of their loss, thus enabling preventative interventions to be offered.

Four Determinants of the grief response (Worden, 1985)

- i) *The nature of the attachment:* accordingly here the most intense and difficult grief responses are said to occur when the attachment to what is lost was very strong or ambivalent, or where what is lost served a function in supporting an individual's sense of self worth and self esteem. Each of these scenarios can be understood within the context of IVF treatment. Couples make a heavy investment in the treatment process. Those falsely imagining themselves to be pregnant when their embryos are in-utero, make an attachment which has to be grieved for when the reality of the procedure's failure is discovered. Additionally, as motherhood is

seen as central to the formation of the female identity, providing a context for women's lives and for how they relate to others (Woollett, 1992), the loss of fertility potentially throws into question a woman's concept of self.

ii) *The form taken by the loss*: a sudden loss may be more difficult to accept than one with advance warning. In this respect, unsuccessful treatment may be easier to comprehend when one is realistic about the chance of success, however, many couples deny the relevance of IVF 'statistics', believing that they will be able to 'beat the odds' (Dennerstein & Morse, 1988).

iii) *Historical antecedents*: how well individuals have reacted to previous losses often plays a role in their response to current loss. Woollett (1992) suggests that women feel more confident in their ability to handle the disappointment of unsuccessful IVF treatment when they have coped well following relationship break-ups or the loss of a parent. Having such experiences enables them to recognise that the feelings will, over time, become less painful and overwhelming.

iv) *Social factors*: belonging to a social structure which actively supports the expression of grief and which provides guidelines and rituals for grieving behaviour is likely to increase the probability of a positive grief outcome. Unfortunately, because the loss following unsuccessful IVF is a potential rather than an actual one, others often seek to trivialise and denigrate it. Individuals within the social environment find it difficult to relate to something which for them is not tangible, and thus see little need for supportive rituals to assist the infertile in bearing the

pain of their loss. Clearly, allowing oneself permission to grieve, is made more difficult when those around do not accept the existence of the loss.

1.8 Is There A Need for Therapeutic Intervention with the Infertile?

Within the literature there exists some consensus regarding the need for counselling services for infertile individuals (Shaw, Johnston & Shaw, 1988), although what form this should take, when it should be provided, and to whom, are questions which remain under debate (Edelmann and Connolly, 1994). Given then that the psychological and therapeutic needs of this population are essentially unknown, ascertaining the extent to which current service provision is appropriately focused is almost impossible.

Following the recommendations of the Warnock Committee report (Department of Health & Social Security, 1984) licensed infertility clinics are now required by law to make counselling available to all patients who are considering consenting to IVF treatment. One of the central aims of this is to provide couples with the opportunity to discuss with an impartial person, the emotional implications of the proposed treatment for themselves, their families and any child born (HFEA, 1997). The emphasis placed upon counselling varies between clinics, with some insisting upon it before certain treatments are given and others offering it both pre and post treatment.

According to clinic infertility counsellors, patients seldom access 'in-service' counselling (Personal Communication). Whilst there is little research evidence to explain this poor uptake, various hypotheses are proposed. For example, counsellors can rarely be completely impartial; as employees of clinics they play some part in assessing the suitability of individuals for treatment. It is therefore not surprising that

patients do not feel 'free' to access a service where their vulnerabilities and anxieties may be exposed, and following which they may be screened out of receiving treatment. Similarly, in cases where treatment is unsuccessful and the decision to stop has to be made, patients often feel angry, severing all links with the clinic, and thus ignoring follow-up appointments offered to them.

Whilst there is no evidence to suggest that infertility is associated with major psychopathology (Edelmann & Connolly, 1994), individuals undergoing IVF treatment are more susceptible to affective disorders than the normal population, with differences also existing between the sexes (Johnston et al., 1987). Previously, both group, couple and individual counselling strategies have been employed with the central aim of enhancing effective coping and reducing the emotional 'toll' on individuals created by their infertility and its treatment (Read, 1995). Moreover, it has been suggested that counselling, as well as providing the necessary supportive structure for individuals receiving treatment, it should be used as a 'vehicle' for facilitating couples' IVF decision making (Edelmann & Connolly, 1994).

1.9 Rationale for the Current Study

The extent to which couples are able to adjust to their childless status successfully, following treatment termination may be affected by various factors. The eventual decision to end treatment may for some bring a sense of relief and an opportunity to move on with life, but for others this may not be the case (Baram et al., 1988). In summary, all that is known is that individuals employ a variety of strategies to assist them in coping and managing their infertility and the painful process of unsuccessful treatment. However, in order to understand what happens to individuals who

discontinue treatment, a methodological approach which allows a theoretical framework to be developed related specifically to these individuals and their experience should be utilised.

Reactions to unsuccessful IVF treatment are not universally similar, and therefore one would not expect uniformity within responses and within adaptation to treatment termination. However, in identifying the characteristics of individuals associated with an increased risk of adverse reactions, this introduces the possibility of some preventative action being formulated for clinical intervention in this area.

Clearly, individuals with fertility problems have psychological needs which may or may not be met. Receiving IVF treatment is known to be a physically and emotionally stressful process, the impact of which can induce psychological crises, and although some individuals have a repertoire of psychosocial, and other more practical resources to help them in managing this process, others do not and as such, may require more professional support and guidance. Whilst specialist infertility counselling services do exist within treatment settings to facilitate this process, few in practice partake and it is highly likely then that these individuals are accessing help through other therapeutic routes, which could include Clinical Psychology services. An exploration of the nature of the interaction between Clinical Psychologists and these individuals is therefore indicated, this being the focus of the first section of this investigation.

Furthermore, developing our understanding of the therapeutic experience of the subgroup for whom a decision to terminate treatment has been made, is similarly important. These individuals have shown through their initial accessing of treatment

services, that they are inclined to pursue active ways of managing their difficulties. However, what is not known is whether they take similar active coping steps once the eventual decision to stop treatment is made. For example, do they seek professional psychological support to aid their adjustment?; or alternatively, are some encouraged to engage in this help seeking behaviour, perhaps by being referred to services for reasons other than for the issue of their infertility? The focus for the second section of this investigation is therefore toward exploring the largely overlooked experiences of this sub-group.

2. Research Questions

The following research questions will be addressed:

2.1 Section One (Quantitative)

How much contact do Clinical Psychologists report having with individuals and couples who experience problems related to their infertility, unsuccessful infertility treatment and decisions to stop infertility treatment?

- Is it usual for these clients to be referred to services with problems related or unrelated to their infertility?
- Once in therapy, how often is dealing with issues related to infertility identified as the primary therapeutic task?
- Are many Clinical Psychologists working with clients where adjustment following the decision to terminate infertility treatment is the central issue?

2.2 Section Two (Qualitative)

In the tradition of grounded theory, no specific hypotheses were generated prior to data collection within this section of this current study. The following tentative research questions guided the design of the semi-structured interview topic guide and shaped the course of the interviews, as well as facilitating the process of data analysis. Additionally, by taking an inductive approach it was hoped that other issues would emerge as the study progressed.

How do individuals experience the decision to stop IVF treatment? Are there factors which will predict the level of an individual's perceived adjustment and coping following this decision? (Are these common to both sexes?)

- i) Is a couples' perceived ability to adjust affected by the manner in which the decision to discontinue IVF treatment originated?
- ii) Is perceived ability to manage and cope affected by an individual's construction and/or understanding of the IVF treatment failure?
- iii) Is an individual's perceived adaptation to their childless status influenced by their access to and /or perceived usefulness of counselling services?
- iv) What role does an individual's network of social support play in their perceived level of adjustment?
- v) To what extent does the course of treatment and point at which it fails affect individual's perceived coping?
- vi) To what extent do couples explore other alternative ways of becoming parents to help them cope?
- vii) Does a couples' perceived quality of their marital relationship affect the course of perceived adjustment and coping?

2.3 Reasons for choosing a qualitative research methodology

The current research is at an early stage of enquiry in an area largely unexplored by previous investigations. A qualitative grounded theory approach (Strauss, 1987) was therefore deemed to provide the most suitable research methodology for this section of the investigation. This approach would allow the personal and social experiences of individuals who discontinue IVF treatment to be explored, understood and described, and would thus enable a theoretical framework to be developed around this experience.

Grounded theory is based upon an inductive approach whereby theory is 'grounded in' the personal experiences of research participants rather than being a reflection of the researcher's *a priori assumptions*, as is the case in quantitative research paradigms (Bannister, Burman, Parker, Taylor & Tindall, 1994). It provides the researcher with analytic techniques for handling and making sense of what seems initially to be ill-structured data (Henwood & Pigeon, 1995), whilst incorporating rigorous procedures for the researcher to check, refine and develop ideas and intuitions about the research material (Pigeon, 1996). Likewise, this approach allows the researcher to uncover new meanings and understandings (Bannister et al., 1994), therefore, making it an appropriate methodology for an inductive phase of research (Orford, 1995).

3. Methodology - Section One

3.1 Ethical Approval

Due to the nature of the investigation it was deemed necessary to obtain ethical approval from two independent Research Ethics Committees. For section one of the investigation ethical approval was sought and obtained from the Salomons Centre Research Ethics Committee (Appendix 1).

3.2 Design

A survey design was employed for this section of the investigation.

3.3 Participants

3.3.1 *Recruitment*

In order to survey the large, national sample of Clinical Psychologists intended, 1000 questionnaires were sent to a sample of Clinical Psychologists randomly selected from the total membership of the British Psychological Society's (BPS) Division of Clinical Psychology. The direct mail service offered by the BPS was employed to facilitate this.

3.3.2 *Description of the sample*

Of the 1000 questionnaires distributed, 436 were returned over a period of six weeks, giving a response rate of 43.6 per cent.

As can be seen from Table 1, a wide range of clinical specialities were represented within the sample. However, the majority of respondents worked in adult mental health settings, perhaps reflecting the distribution of psychologists within the

profession as a whole. Clinical Psychologists working in services dedicated to infertility constituted only 1.3 per cent of the sample.

Table 1 - The client groups within which the participant Clinical Psychologists work

Client Group	Frequency	Percentage
Adult Mental Health	146	36.9
Child & Family	56	14.1
Split Posts	35	8.8
Learning Disability	33	8.3
Primary Care	23	5.8
Older Adults	21	5.3
Trainee	20	5.1
Health	18	4.5
Forensic	12	3.0
Neuropsychology	8	2.0
HIV & Sexual Health	8	2.0
Infertility Services	5	1.3
Substance Misuse	5	1.3
Brain Injury	3	0.8
Private Practice	2	0.5
Eating Disorders	1	0.3
Total	396	100
Not Stated	40	9.2
Total	436	

3.4 Measures

'Sub-fertility: frequency of contact with therapeutic services - A survey' (Appendix 2)

The survey instrument was developed following discussions with Counsellors and medical personnel working within the infertility services at two London teaching hospitals, and Clinical Psychologists working within local primary and secondary mental health care services. The aim was to survey Clinical Psychologists regarding their therapeutic contact with persons with fertility problems; exploring in particular, the frequency and means by which these people accessed psychology services for help with issues related to their fertility problems, failed fertility treatment and decisions to stop fertility treatment.

The survey instrument was designed so as to be brief and easily completed. It was, therefore, contained on a single A4 sized piece of paper, and included five questions to be answered. Prior to submission for ethical approval the survey was piloted with a small group of clinical and research psychologists. Following this some minor format changes were made to improve the ease with which it could be completed, and to facilitate the later interpretation and analysis of responses.

3.5 Procedure

One thousand copies of the questionnaire were, along with 1000 pre-paid envelopes sent directly to the BPS who, using their membership database distributed them to a random sample of Clinical Psychologists. Upon receipt of the questionnaire, clinicians were asked to complete and return it anonymously, if they were currently, or had in the past worked within a therapeutic setting. Clinicians were asked to estimate the number of individuals that they had seen within their practice career, at the various stages along the infertility diagnosis and treatment process. In addition to this, they were asked to consider the referral routes for these individuals and the therapeutic tasks worked on during sessions.

Participants were able to make any qualitative comments that they wished to on the reverse of their survey sheet. They were also provided with an address at which to contact the researcher to receive a short report of the research findings; eight of the final respondents requested this.

3.6 Data Analysis

Descriptive statistical analysis was carried out to provide detailed summary statistics concerning individuals' with fertility problems and their use of psychological services. This analysis was completed utilising the Statistical Package for Social Scientists (SPSS) computer programme.

4. Methodology - Section Two

4.1 Ethical Approval

Prior to seeking ethical approval for the qualitative interview section of the investigation various meetings were held with medical personnel from two Assisted Conception Units, based within two London teaching hospitals. As a result of the concerns expressed by the first unit regarding anticipated difficulties in recruiting participants, a decision was made not to approach the Research Ethics Committee for this institution. The second unit were, however, more positive in their response, indicating that potential participants were indeed known to their unit, and that they would be happy to support recruitment. Ethical approval was thus sought and obtained from this hospital's Research Ethics Committee (Appendix 3).

4.2 Design

A cross-sectional design was employed, using a qualitative methodological approach. Personal in depth interviews were carried out with participants, using a semi-structured interview format to explore the issues for individuals for whom a decision to discontinue IVF treatment had been made.

By adopting a qualitative approach it was possible to obtain a more detailed and personal account regarding the nature of participants' adjustment and coping, and their overall psychological well-being; looking specifically at the meaning which participants attached to their own experience. Furthermore, this approach allowed for the effect on participants of other life events and circumstances to be taken into account.

4.3 Participants

4.3.1 *Recruitment*

The sample was drawn from a population of patients attending the Assisted Conception Unit of one of London's teaching hospitals. The criteria for inclusion were that participants, both men and women, should have undergone one or more unsuccessful courses of IVF treatment, and that a decision to terminate treatment should have been made not more than twelve months ago.*

A letter and information leaflet (Appendix 4 & 5) were sent to a total of 43 couples who met the above inclusion criteria, and whose names were identified through a 'trawl' of the unit's inactive case notes. In addition to this, three information leaflets were given out by the unit's Counsellor, and the unit's support group organiser was approached to establish whether she knew of any potential participants to whom information leaflets could be sent; this resulted in one further couple being approached.

* This criterion is a guide only, as the passage of time from the approach to participate and actual interview will inevitably result in some margin of months higher than 12, potentially.

4.3.2 Description of sample

A total of 47 couples (94 individuals) were invited to be interviewed for this part of the study, by letter or through direct contact with the unit's counsellor or support group organiser. Of these, six couples and two individuals ($N = 14$) returned the 'tear off' section of the information leaflet indicating that they would like to take part; giving a response rate of 14.9 per cent. Eleven individuals agreed to be interviewed following telephone contact with the researcher; one couple were unable to take part because the female partner had been admitted to hospital, and a single female respondent had relocated to another part of the country and an interview with her was therefore not feasible. Every participant chose to be interviewed in their own home, with all couples requesting to be interviewed together.

As can be seen from Table 2, the mean age of participants was 37.27 years ($SD = 2.05$), with a range of 34 to 42 years; the mean age for male participants ($N = 5$) was 37.20 years ($SD = 3.03$) and the mean age for female participants ($N = 6$) was 37.33 years ($SD = 1.03$). At the time of interview, two thirds of the sample were in full time employment. All were married and had, on average, been with their partners for 12.36 years ($SD = 2.06$) years.

The mean number of years participants had spent trying for a baby was 7.27 ($SD = 3.38$), and for all but one there was no identified explanation for their infertility. Four of the five couples experienced primary infertility whilst the remaining three participants had previously conceived children, and had therefore been diagnosed as having secondary infertility problems. The total number of IVF treatment cycles undertaken by participants was 27, with 85.2 per cent of cycles funded by the NHS and

14.8 per cent paid for by participants themselves. Finally, the mean numbers of months following participants' last treatment cycle and their decision to stop treatment was 10.27 (SD = 4.43).

Table 2 - Demographic details of sample (N = 11)

	Gender	Age	Employment details	No. of years with partner	No. of years trying to conceive	Cause of infertility	No. of treatment cycles	NHS or self funded (SF)	No. of months post decision	No. of children from this or prior rels.
1	Male	38	Full-time	14	13	Primary - Unexplained	4	1 - SF	9	0
2	Female	37	Part-time	14	13	Primary - Unexplained	4	3 - NHS 1 - SF	9	0
3	Male	36	Full-time	10	7	Primary - Unexplained	3	NHS	6	0
4	Female	37	Full-time	10	7	Primary - Unexplained	3	NHS	6	0
5	Male	34	Full-time	13	5	Primary - Unexplained	1	SF	9	0
6	Female	38	Full-time	13	5	Primary - Unexplained	1	SF	9	0
7	Male	42	Full-time	15	9	Secondary - Unexplained	3	NHS	12	1
8	Female	36	Part-time	15	9	Secondary - Unexplained	3	NHS	12	1
9	Female	37	Unemployed	12	4	Secondary - damage to ovary/tube	1	NHS	5	1
10	Male	36	Full-time	10	4	Primary - Unexplained	2	NHS	18	0
11	Female	39	Full-time	10	4	Primary - Unexplained	2	NHS	18	0

4.4 Measures

Semi-structured interviews were carried out with participants using an open-ended conversational style. In order to gain ethical approval to carry out these interviews it was important to develop an interview topic guide (Appendix 6). This guide was developed following discussions with personnel within the infertility field, and provided an account of the areas to be explored during the interview process; directing the interviews in this way appeared in no way to undermine the methodological approach being used (see Pigeon & Henwood, 1996, p. 89).

4.5 Procedure

Interviews were conducted within participants' homes and were approximately two hours in duration for those carried out with couples, and one and a half hours with the single participant. Before each interview commenced participants were greeted and briefed about the nature of the investigation; questions about participants' roles and the format for the eventual presentation of the findings were answered. Each participant was asked to complete a consent form confirming their agreement to take part in the study, and to give their written consent to the making of an audio tape recording of the interview (Appendix 7). All participants agreed to the making of such a recording and each was assured of complete confidentiality.

The interview started once the recording equipment was set going. Participants were asked to begin by providing some demographic information about themselves, including age, employment, relationship and family details. Following this participants were directed, using the interview topic guide, to talk freely about their experiences and feelings across the following three areas:

- i) their experience of the IVF treatment process
- ii) their decision to stop treatment
- iii) their lives 'post decision'

(Prompts were occasionally used to facilitate the exchange of information and to clarify, and follow up comments and responses voiced by participants).

Although for some participants revisiting this painful and distressing time in their life was difficult, the interview format allowed for the containment of this distress and in certain instances may have provided a space for its resolution.

Interviews were terminated when each participant believed that they had shared everything they wished to in each of the areas presented. Following this each participant was debriefed and the researcher enquired as to their general well-being. Participants were given the opportunity to ask any further questions and the following points were reiterated:

- i) that audio tapes once transcribed could be returned to them, if they so wished
- ii) that a written transcript of the interview would be sent to them within the following two to three weeks to enable them to check it's accuracy
- iii) that they could request a copy of the final report which would be sent to them once the research had been completed.

A telephone number for the researcher was supplied to each participant so they could make contact should they wish to discuss anything further subsequent to the interview. Information about support groups and local counselling services was offered to every participant, and details provided to those requesting it. Following this, the recording equipment was switched off and participants were thanked for taking part.

After each interview a typed transcript was made from the audio recording. Once these transcripts had been checked by the researcher, they were sent to participants for checking along with a pre-paid envelope and recommended return date. Although offered, no participant wished to retain their audio tape recording once transcribed, and once agreement had been reached between the researcher and participants regarding the accuracy of the typed transcripts all recordings were erased.

4.6 Data Management

The aim of the analysis was to develop a theoretical framework around adjustment and coping following termination of IVF treatment, utilising aspects of the grounded theory approach to qualitative analysis (Strauss & Corbin, 1990).

The interview transcripts were all analysed individually. Although the method, as outlined by Strauss and Corbin (1990), requires data collection and analysis to occur simultaneously so that emerging themes can shape further data collection, this was not practically possible (this process has been described as 'ambitious'; Henwood & Pigeon, 1995). Analysis had therefore to follow data collection.

The analytic sequence was as follows:

1. Immersion

The analysis began with a process of reading and re-reading the data to promote familiarity.

2. Coding

Next, the text of each interview was analysed sentence by sentence. Meaningful segments of text, expressing single coherent thoughts were then underlined and labelled as basic codes. These basic codes were gradually modified and extended as further transcripts were analysed.

3. Categorisation

Here, basic codes which appeared related to each other, within and across interviews, were grouped together into initial categories to describe the main features of the data. Categories were defined and illustrated using relevant quotations from the interviews.

4. Inter-rater reliability

At this stage of the analysis an independent rater was employed to categorise two randomly selected interview transcripts. (See Appendix 8 for inter-rater reliability study procedure).

5. Thematic analysis

Core themes were then identified across interviews by examining the emergent categories and looking for possible connections and differences between them. These themes were explored and developed further through discussion with the researcher's supervisor.

6. Construction of a theory

The final stage of the analysis aimed to construct an emerging theoretical framework based upon the interpretation of categories and themes generated from the data.

Although it was not possible within the parameters of the present study, further theoretically driven sampling is required to build upon the present analysis and to test the emerging theory.

4.7 **Reliability and Validity**

This study employed various methods to maximise both reliability (procedural trustworthiness) and validity (trustworthiness of interpretations), as defined for use in qualitative approaches by Stiles (1993).

4.7.1 *Auditability*

Throughout the course of the research, a diary was kept to provide a reflexive account of the research process, revealing the interpretative processes, stance and subjective experiences of the researcher (Appendix 9). (The researcher's reflections on individual interviews were informed by material contained within this diary). The process of analysis was also thoroughly documented and meticulous records kept of all participants' interviews. Overall, this constitutes an 'audit trail' (Lincoln & Guba, 1985), and enables the research process to be scrutinised by others.

4.7.2 *Inter-rater reliability*

In order to assess the accuracy and generalisability of the analysis an independent rater categorised selected examples of text using the codes and categories generated by the researcher. Inter-rater agreement (%) was calculated by comparing the independent raters findings with those of the researcher.

High inter-rater reliability was obtained for both codes and categories, the results of which are presented in Table 3.

Table3 Results of inter-rater reliability for basic codes and categories

Randomly selected interviews	Percentage agreement for codes	Percentage agreement for categories
Interview Five	100	85.7
Interview Six	85.7	88.9

5. Results

5.1 Section One (Quantitative)

5.1.1 The participants working with people with fertility problems

Of the total sample of Clinical Psychologists who completed the survey ($N = 436$), 30.7 per cent ($N = 134$) indicated that they had, during their careers, worked with individuals who experienced problems with fertility. The remainder of the sample, 69.3 per cent ($N = 302$) stated that they had never seen anyone in a therapeutic setting with problems of this nature. The distribution amongst the clinical specialities of the two groups are shown in Tables 4.1 and 4.2 below.

Table 4.1 The client groups Psychologists who have worked with people with fertility problems work within ($N = 134$)

Client Group	Frequency	Percentage
Adult Mental Health	63	48.8
Primary Care	12	9.3
Split Posts	12	9.3
Health	12	9.3
Child & Family	10	7.8
Infertility Services	5	3.9
HIV & Sexual Health	5	3.9
Older Adults	3	2.3
Learning Disability	2	1.6
Private Practice	2	1.6
Brain Injury	1	0.8
Forensic	1	0.8
Trainee	1	0.8
Total	129	100
Not stated	5	3.7
Total	134	

Table 4.2 The client groups Psychologists who have not worked with people with fertility problems work within ($N = 302$)

Client Group	Frequency	Percentage
Adult Mental Health	83	31.1
Child & Family	46	17.2
Learning Disability	31	11.6
Split Posts	23	8.6
Trainee	19	7.1
Older Adults	18	6.7
Forensic	11	4.1
Primary Care	11	4.1
Neuropsychology	8	3.0
Health	6	2.2
Substance Misuse	5	1.9
HIV & Sexual Health	3	1.1
Brain Injury	2	0.7
Eating Disorders	1	0.4
Total	267	100
Not stated	35	11.6
Total	302	

Excluding those working in specialist infertility services, it may be seen from Tables 4.1 and 4.2 that those within the sample who are working in the health field had the largest percentage of contact with clients with fertility problems (12 out of 18, equalling 66.66%). Sixty-three per cent of Clinical Psychologists (5 out of 8) working in HIV and sexual health services had contact with these clients, while 52 per cent (12 out of 23) of those working in primary care did also.

5.1.2 The types of clients seen by participants

As can be seen from Table 5.1 the largest proportion of clients seen by Clinical Psychologists, **outside of the specialist infertility services** were those who were undergoing infertility treatment during therapy¹. Clients appeared less likely to be accessing psychological services if they had as yet had no treatment for infertility but intended to in the future.

Table 5.1 Frequency and percentage of Clinical Psychologists who reported working with clients in each of the 6 identified fertility categories (excluding those psychologists working in specialist infertility services) N = 129

Categories of Clients with Fertility Problems		1. Having fertility treatment during therapy	2. Had successful fertility treatment (child born)	3. Had unsuccessful fertility treatment & intending to try again	4. Had unsuccessful fertility treatment & decision to stop made	5. Had no fertility treatment ever	6. Had no fertility treatment, but intending to in the future
Worked with this category of infertility client	Yes N (%)	77 (59.7)	54 (41.9)	58 (45.0)	52 (40.3)	51 (39.5)	31 (24.0)
	No (%)	52 (40.3)	75 (58.1)	71 (55.0)	77 (59.7)	78 (60.5)	98 (76.0)

Of those Clinical Psychologists **working in specialist infertility services**, 100 per cent (N = 5) reported having worked with clients in categories one, three and four; 80 per cent (N = 4) had worked with clients in category two, whilst only 20 per cent (N = 1) had worked with clients in categories five and six.

When asked to estimate the number of men, women and couples they had seen therapeutically within each of the six categories, the overall client contact numbers for participants' **not working in infertility services** were small (Table 5.2). Contact with larger numbers of female, as opposed to male clients, was consistently reported; with men more likely to have accessed services if they were part of a couple.

¹ In order to avoid a skew in the overall survey results a decision was taken to analyse the responses of Clinical Psychologists working in specialist infertility services separately (N = 5)

Table 5.2 - The reported frequency and percentage of Clinical Psychologists not working in infertility services seeing men, women, and couples in the six fertility categories (N = 129)

No. of clients seen	Cat.1			Cat.2			Cat.3			Cat.4			Cat.5			Cat.6		
	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples
None	111 (86.0)	70 (54.3)	93 (72.1)	120 (93)	93 (72.1)	103 (79.8)	121 (93.8)	89 (69.9)	101 (78.3)	123 (95.3)	96 (74.4)	104 (80.6)	114 (88.4)	87 (67.4)	107 (83.0)	121 (93.8)	107 (82.9)	117 (90.7)
1-4	13 (10.1)	49 (38)	28 (21.7)	4 (3.1)	30 (23.3)	20 (15.5)	4 (3.1)	35 (27.1)	23 (17.8)	2 (1.6)	28 (21.7)	22 (17.1)	8 (6.2)	31 (24.0)	12 (9.3)	5 (3.9)	19 (14.7)	9 (7.0)
5-9	0	3 (2.3)	1 (0.8)	0	0	1 (0.8)	0	0	1 (0.8)	0	2 (1.6)	0	0	3 (2.3)	0	1 (0.8)	0	0
10+	5 (3.9)	7 (5.4)	7 (5.4)	5 (3.9)	6 (4.6)	5 (3.9)	4 (3.1)	5 (3.9)	4 (3.1)	4 (3.1)	3 (2.3)	3 (2.3)	7 (5.4)	8 (6.2)	10 (7.7)	2 (1.6)	3 (2.3)	3 (2.3)

Table 5.3 - The reported frequency and percentage of Clinical Psychologists working within infertility services seeing men, women, and couples in the six fertility categories (N = 5)

No. of clients seen	Cat.1			Cat.2			Cat.3			Cat.4			Cat.5			Cat.6		
	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples	Men	Women	Couples
None	5 (100)	4 (80)	1 (20)	5 (100)	5 (100)	1 (20)	5 (100)	4 (80)	1 (20)	5 (100)	4 (80)	1 (20)	5 (100)	5 (100)	4 (80)	5 (100)	5 (100)	4 (80)
1-4	0	1 (20)	1 (20)	0	0	2 (40)	0	1 (20)	1 (20)	0	1 (20)	2 (40)	0	0	1 (20)	0	0	1 (20)
5-9	0	0	0	0	0	1 (20)	0	0	0	0	0	1 (20)	0	0	0	0	0	0
10+	0	0	3 (60)	0	0	1 (20)	0	0	3 (60)	0	0	1 (20)	0	0	0	0	0	0

Clinical Psychologists working within specialist infertility services reported seeing no lone male clients in any of the six category areas (Table 5.3). Of the three presented client groups, couples were most commonly seen therapeutically. Sixty per cent of participants indicated that they had seen more than 10 couples for therapy who were either having infertility treatment at the time, or who had unsuccessful treatment and were intending to try again.

5.1.3 The reasons for clients' referrals

Overall, as shown in Table 6.1 for those **not working in infertility services**, referrals requesting input for individuals experiencing *adjustment difficulties following a decision to stop infertility treatment*, were least common, with half of those responding assigning a rank of four to this reason (rank 1 indicates most common to rank 4 least common). Interestingly, two thirds of participants noted that, in their experience, individuals with fertility problems were most commonly referred to services for issues unrelated to their infertility.

Table 6.1 Number & percentage breakdown of participants (not working in infertility services) assigning frequency rank to each reason for referral (rank 1 = most common to 4 = least common)

	Rank 1 N (%)	Rank 2 N (%)	Rank 3 N (%)	Rank 4 N (%)	Mean Rank SD	Mode Rank	Total N
Fertility problems	46 (49.5)	18 (19.4)	14 (15.1)	15 (16.1)	1.98 (1.14)	1	93
Unsuccessful treatment	11 (13.8)	41 (51.3)	21 (26.3)	7 (8.8)	2.30 (0.82)	2	80
Decision to stop treatment	3 (4.1)	6 (8.2)	27 (37.0)	37 (50.7)	3.34 (0.80)	4	73
Unrelated to fertility	76 (66.7)	17 (14.9)	7 (6.1)	14 (12.3)	1.64 (1.05)	1	114

Although not directly required by the survey, some participants provided examples of the 'problems' ascribed by referrers to their clients with fertility problems. These reasons for referral were consistently linked to clients' mental health status or

relational difficulties, with specific problems such as anxiety, depression and 'stress' frequently reported.

In contrast, referrals to Clinical Psychologists working in specialist infertility services were most commonly reported as being explicitly related to the clients' problems with fertility and treatment failure (Table 6.2).

Table 6.2 Number & percentage breakdown of participants (working in infertility services) assigning frequency rank to each reason for referral (rank 1 = most common to 4 = least common)

	Rank 1 N (%)	Rank 2 N (%)	Rank 3 N (%)	Rank 4 N (%)	Mean Rank (SD)	Mode Rank	Total N
Fertility problems	3 (60)	2 (40)	0	0	1.40 (0.55)	1	5
Unsuccessful treatment	2 (40)	3 (60)	0	0	1.60 (0.55)	2	5
Decision to stop treatment	0	0	4 (80)	1 (20)	3.20 (0.45)	3	5
Unrelated to fertility	0	0	1 (20)	4 (80)	3.80 (0.45)	4	5

5.1.4 The task of therapy, as identified by participants

Clinical Psychologists not working in infertility services identified *coping with infertility* as the most common task for therapeutic work with clients with fertility problems. However, when assigning a rank of importance to the statement that *infertility was not a task for therapy* participants' views were polarised; nearly equal numbers identified it as their most and least common task for therapy (Table 7.1).

Table 7.1 Number & percentage breakdown of participants (not working in infertility services) assigning frequency rank to each therapeutic task (rank 1 = most common to 4 = least common)

	Rank 1 N (%)	Rank 2 N (%)	Rank 3 N (%)	Rank 4 N (%)	Mean Rank (SD)	Mode Rank	Total N
Coping with infertility	61 (59.8)	26 (25.5)	7 (6.9)	8 (7.8)	1.63 (0.92)	1	102
Adjustment following decision to stop treatment	11 (14.3)	14 (18.2)	33 (42.9)	19 (24.7)	2.78 (0.98)	3	77
Coping with unsuccessful treatment	26 (29.9)	31 (35.6)	21 (24.1)	9 (10.3)	2.15 (0.97)	2	87
Infertility not a task	41 (40.2)	10 (9.8)	6 (5.9)	45 (44.1)	2.54 (1.40)	4	102

For those working within specialist infertility services coping with issues related to clients' infertility was identified as the most common task of therapy. *Infertility not a task for therapy* was agreed by all to be the least common therapeutic task (Table 7.2).

Table 7.2 Frequency & percentage breakdown of participants (working in infertility services) assigning which rank to each therapeutic task (rank 1 = most common to 4 = least common)

	Rank 1 N (%)	Rank 2 N (%)	Rank 3 N (%)	Rank 4 N (%)	Mean Rank (SD)	Mode Rank	Total N
Coping with infertility	3 (60)	2 (40)	0	0	1.40 (0.55)	1	5
Adjustment following decision to stop treatment	0	1 (20)	4 (80)	0	3.00 (0)	3	5
Coping with unsuccessful treatment	1 (20)	2 (40)	1 (20)	1 (20)	2.25 (1.26)	2	5
Infertility not a task	0	0	0	4 (80)	3.25 (1.50)	4	5

5.1.5 Therapeutic outcome

Finally, participants were asked to indicate whether or not they had a sense that a resolution of clients' fertility issues was achieved by the end of therapy. Few indicated that such a resolution was always the case. Just under half of those not working in specialist infertility services, and 60 per cent of those within infertility services adopted the neutral 'sometimes' stance.

Table 8.1 Participants not working in infertility services: the extent to which a resolution of fertility issues was achieved during therapy

	Frequency (%)
Never	16 (12.9)
Rarely	23 (18.5)
Sometimes	54 (43.5)
Quite Often	24 (20.2)
Always	6 (4.8)
Missing	5
Total	129

Table 8.2 Participants working in infertility services: the extent to which a resolution of fertility issues was achieved during therapy

	Frequency (%)
Never	0
Rarely	0
Sometimes	3 (60)
Quite Often	2 (40)
Always	0
Total	5

5.1.6 Summary of section one results

From the above analysis it would seem that a large percentage (69.3%) of Clinical Psychologists appear not to have worked with individuals with fertility problems.

Those who did report contact with this client group, (29.6%; excluding those in specialist infertility services), were more likely to have engaged therapeutically with female as opposed to male clients, with those undergoing infertility treatment during therapy essentially receiving the most Clinical Psychology service resources. Moreover, whilst it appeared usual for clients to be referred to Clinical Psychologists for problems *unrelated to their infertility*, the primary therapeutic task was more often than not identified as *dealing with issues of infertility*.

The second stage of this study is concerned primarily with those individuals for whom infertility treatment has been unsuccessful and a decision made to stop. Before the results of the qualitative analysis of this sub-group are presented, the survey data pertaining to them will be explored in more detail.

5.1.7 Individuals who have discontinued unsuccessful infertility treatment

Of the total group of Clinical Psychologists who had worked with individuals with fertility problems, 52 (40.3%¹) indicated that they had worked with clients who had discontinued unsuccessful infertility treatment.

As shown in Table 9, this sub-group appear to present to a variety of services. Of all the Clinical Psychologists who reported working with clients with fertility problems, all those working within private practice and older adult services indicated having had contact with clients in this infertility category. Similarly, 58.33 per cent of Clinical Psychologists in primary care services reported contact with this sub-group.

¹This percentage excludes those Clinical Psychologists working within specialist infertility services (N = 5). All these psychologists stated that they had worked with clients who had unsuccessful treatment and decided to stop

Table 9 The services psychologists work within where clients who have discontinued unsuccessful fertility treatment present (N=52)

Client Group	Freq. (%) N = 52	% total of CPs within each client grp working with these clients (%)
Mental Health	27 (51.9)	42.9
Primary Care	7 (13.5)	58.33
Child & Family	4 (7.7)	40.0
Split Posts	4 (7.7)	33.33
Health	3 (5.8)	25
Older Adults	3 (5.8)	100
Private Practice	2 (3.8)	100
HIV & Sexual Health	2 (3.8)	40

Referrals for this sub-group were not commonly related to their decision to discontinue treatment; the mean rank assigned to this reason was 3.2, where rank 4 is the least common reason (SD = 0.98). Nor was this reason (i.e. decision to discontinue treatment) identified as the most common task of therapy (mean rank = 2.59, SD = 0.96).

5.2 Section Two (Qualitative)

5.2.1 Overview

The initial immersion and coding analysis resulted in a total of 254 basic codes being produced across the six interviews (5 couples and 1 individual interview); in most cases these codes were labelled using a literal representation of participants' own words. Through a continued analysis of the interviews, these codes were then modified and further grouped into emerging conceptual categories within interviews, and across the whole sample (see Appendix 10 for a full account of all the categories generated, and the codes subsumed under them).

This section begins by presenting an account of the emerging conceptual categories generated for each interview in turn, using quotations where appropriate to illustrate categories. For each interview three boxes are presented containing the categories which emerged for that couple or individual in relation to the three areas commented

upon (the experience of IVF; the decision to stop; life post-decision); for the five couples, categories are divided within the boxes depending on whether they related to comments made by the male participant, the female participant or both parts of the dyad. Within the text and 'category' boxes, each category, its associated codes (identified in the text within single quotes) and quotations are numbered in square brackets. Categories are correspondingly numbered in Appendix 10. Positive, negative and neutral categories are labelled as such according to whether participants gave a sense of comments in this category having a 'good', 'bad' or 'indifferent' effect on them, and not on the basis of the Researcher's judgement.

This is followed by a description and exploration of the commonalties and differences between the categories, across the whole sample, pulling out the core themes which seem to unify the data and relating these where appropriate to the tentative research questions initially proposed. The emerging theoretical framework is presented in Section 6.5.

5.2.2 Interview One - Mr and Mrs A

Brief description of couple - at the time of their interview Mr and Mrs A (aged 38 & 37 respectively) had been together for 14 years, and trying for a baby for 13. The origin of their infertility was unexplained and primary in nature, and over a period of seven years they had undergone three stimulated IVF treatment cycles and one ICSI cycle, all of which were unsuccessful. Their first cycle was self-funded, with all subsequent attempts funded by the NHS. Nine months had passed since they had made the decision to discontinue treatment.

Reflections of the Researcher - this couple were experienced as being very supportive and sensitive towards each other, even though their views were often different. They were both able to accurately represent each others feelings and opinions, and little which one said seemed surprising to the other. This gave the sense that their communication throughout the IVF experience had been good.

Area one categories (Box 1.1) - Couple A's thoughts about the IVF experience were on the whole fairly negative, although they did recognise that they would have felt differently had their treatment been successful. Mrs A blamed herself for the treatment failure [14] and described 'feeling under pressure to continue with treatment because it was funded' [18]. They both felt that life had been on hold during the IVF process [5],

"I had a good chance of a really good job & because I was having IVF I threw that to one side ... & I've regretted it ever since" [5]

Not informing others about their treatments was perceived as having had negative consequences for them [2],

"we decided not to tell people that we were going through the cycles so at the end of the day it was just the two of us and we had to deal with it" [2]

They believed that their negative feelings were often engendered by the responses of health professionals [16], with codes subsumed within this latter category including 'being treated as though they had an illness' and 'being made to feel that we were a nuisance' [16].

Box 1.1 Conceptual Categories for Couple A : Area One The Experience of IVF	
a. Categories for the male participant - [6] expectations - helpful [10] lack of information - negative	b. Categories for the female participant - [11] general issues about information [14] blaming self for treatment failure [18] financial stresses of treatment
c. Categories for both participants -	
[2] not informing others of treatment - negative [16] negative feelings engendered by health professionals	[5] feeling that life on hold during IVF

Area two categories (Box 1.2) - Both Mr and Mrs A described giving up treatment as a loss [27] which they struggled to know how to cope with. This was made more difficult for them because they also felt abandoned [28] by the Assisted Conception Unit (ACU),

"they just made no attempt to speak to us, we weren't offered any follow-up ... you're in their faces for weeks and weeks having treatment & scans, lets face it they see the most vulnerable side of you & then all of a sudden you're not there anymore, and you think oh well I've been forgotten" [28].

Couple A perceived their 'unexplained' infertility as a negative factor [33]. Codes within this category included 'needing an explanation for why it didn't work' and 'finding it difficult to give up hope because haven't been told it's impossible'.

Mrs A believed that the decision to stop was made easier for her because she 'decided for herself' [43], describing positive feelings once treatment had ended [23],

"I did wake up in hospital and think that is it no more treatment, nothing & I felt relief, total & utter relief ... since I came to that decision I feel much better, I feel much more relaxed and calmer and I've been more healthy" [43 & 23].

She stressed the importance of time for oneself [47] in facilitating coping, with codes here including 'taking time for self reflection' and 'going part-time at work'. In contrast to this Mr A seemed to cope 'by throwing self into other activities' [25].

Box 1.2 Conceptual Categories for Couple A - Area Two The Decision to Stop	
a. Categories for the male participant [31] no need for formal support services	b. Categories for the female participant [22] difficulties in communicating [23] positive feelings once treatment has ended [29] general areas in which support was lacking [38] having different coping styles - positive [43] general factors which made adjustment to stopping easier [47] importance of time for oneself
c. Categories for both participants [20] the importance of communication with partner [27] loss [33] 'unexplained' infertility as a negative factor	
	[25] ways of coping [28] abandonment

Area three categories (Box 1.3) - Life post-decision for Couple A appeared to have been made easier by their ability to positively re-frame life without children [48],

"our relationship & our marriage has been far more important than having children, we're more important, us being together" [48].

although Mr A had not totally given up hope of natural conception [50].

As a couple they were considering adoption as an alternative way of becoming parents, but saw this not as 'a cure for the IVF' [53], but as a 'way of re-evaluating life and working out what we want' [51].

Box 1.3 Conceptual Categories for Couple A : Area Three Life Post-Decision	
a. Categories for the male participant [50] the continued hope of natural conception [61] the 'unjustness' of the world	b. Categories for the female participant [51] adoption - positive aspects [60] feelings towards those with children [64] importance of friendships [65] unhelpful aspects of friendships [66] availability of technology makes adjustment difficult [67] current triggers to distress
c. Categories for both participants [48] positively re-framing life without children [53] adoption - neutral	
	[52] adoption - negative aspects [55] feeling resigned to one's lot in life

5.2.3 Interview Two - Mr and Mrs B

Brief description of couple - at the time of their interview Mr and Mrs B (aged 36 & 37 respectively) had spent seven years of their 10 year relationship trying unsuccessfully to conceive. Their primary infertility was unexplained. They had undergone one stimulated IVF treatment cycle, and two ICSI cycles. Before beginning treatment they were told that NHS funding was available for two IVF cycles. Beyond this, although the procedures were paid for they were required to meet the cost of all medications. The decision to have no further treatment was taken six months ago.

Reflections of the Researcher - Mrs B was at times experienced as being less than 'real'. She was defensive, and her responses were lacking of any real sense of conviction, particularly when she implied that she had not wanted children anyway.

Mr B on the other hand was rather subdued, only speaking when asked directly to comment. He appeared almost indifferent to the whole IVF experience, which frustrated Mrs B. However, the extent to which this behaviour served a protective function for him was unclear.

Area one categories (Box 2.1) - Couple B thought their experience of unsuccessful IVF had been made more difficult by unhelpful expectations [7], with codes within this category including 'having hopes built up by health professionals' and 'the unit making it seem as easy as going out and catching a train'. Mrs B felt 'emotionally unprepared' [10] for the effect of IVF, whereas Mr B indicated that he found dealing with treatment disappointments easy because he was 'realistic about the chance of success' [6].

Box 2.1. Conceptual Categories for Couple B - Area One: The experience of IVF	
a. Categories for the male participant [4] reasons for not informing others [6] expectations - helpful	b. Categories for the female participant [10] lack of information - negative
c. Categories for both participants [7] expectations - unhelpful	

Area two categories (Box 2.2) - The decision to stop treatment was largely perceived by couple B as being finance driven [46], although Mrs B felt that the emotional strain of IVF was also a factor for her in stopping [44]. Mr B identified the helpfulness for him of being prepared for ending at the beginning of treatment [45],

"having a set limit [on the number of treatments] was good, three was always our maximum or otherwise you just get engrossed in it I reckon & you just keep going" [45].

Mrs B coped with treatment ending by 'throwing herself into other activities' and 'trying not to ruminate on what might have been' [25]. She described 'feeling relieved when treatment ended' [23], and both her and her husband stressed the value to them of taking 'holidays' and having time for oneself [47].

Box 2.2 Conceptual Categories for Couple B : Area Two The Decision to Stop	
a. Categories for the male participant [45] helpfulness of being prepared for ending at the beginning of treatment	b. Categories for the female participant [19] taking control yourself of the situation [20] the importance of communication with partner [23] positive feelings once treatment has ended [25] ways of coping [31] no need for formal support [44] stopping because of emotional strain
c. Categories for both participants [24] negative feelings once treatment has ended [46] finance driving the decision to stop [47] importance of time for oneself	

Area three categories (Box 2.3) - Both Mr and Mrs B made comments which suggested they were trying to positively re-frame life without children [48],

"you just get on with your life again & you do lots of things that other people with kids can't. So you're looking at the positive rather than getting depressed about not having kids ... there's so much more you can do ... going on holidays & spending our money really" [48].

Mrs B also appeared to be constructing an identity for herself without children [49],

"I've never been particularly maternal ... I just don't think that being a mother is the be all & the end all & every reason why I am here, it's not there's more to it" [49].

However, they were both secretly 'hanging onto the glimmer of hope' that they would conceive naturally [50].

Mrs B found sharing experiences with others [56] supportive, but as a couple they experienced on occasions some unhelpful aspects of friendships [65]. Codes within this category included 'friends worry that we will feel left out' and 'friends putting pressure on us to try again' [65].

Box 2.3 Conceptual Categories for Couple B : Area Three Life Post-Decision	
b. Categories for the female participant [49] constructing an identity for self without children [53] adoption - neutral [56] sharing experiences with others [63] receiving support from family	
c. Categories for both participants [48] positively re-framing life without children [50] the continued hope of natural conception [65] unhelpful aspects of friendships	

5.2.4 Interview Three - Mr and Mrs C.

Brief description of couple - when interviewed Mr and Mrs C (aged 34 & 38 respectively) had been together for 13 years, and trying to conceive for five. During this time they had funded themselves through one unsuccessful stimulated IVF cycle, and it had been nine months since they had been told by the ACU that they could have no further treatment. This decision was made because Mrs C's ovaries failed to respond when medically stimulated. (Under unit policy couples who failed to produce three good quality embryos were not offered further treatments).

Reflections of the Researcher - The atmosphere throughout this interview was one of intense sorrow and distress. It felt a privilege to have been allowed to hear this couple's story, and to intrude momentarily upon their sadness. They seemed visibly to be struggling to come to terms with the devastating implications for them of treatment ending, at times finding telling their story distressing. However, their feed-back after the interview suggested that they found the experience both helpful and 'therapeutic'.

Area one categories (Box 3.1) - Mrs C's thoughts about the IVF experience were mixed. Whilst she felt that 'having hopes built up by health professionals' [7] was unhelpful, 'being realistic about the chance of treatment success' [6] was perceived as helpful. Moreover, Mrs C felt keeping others informed during the treatment process was important [3],

"I feel better if I can talk to people about things, I don't like to hide it under the carpet ... I made it so they didn't have to tread carefully around me ... I much prefer it that way, it's the sort of person I am, it's the way I handle things" [3].

However, she did at times find it difficult to cope with the cautious responses of her family members to the treatment process [17].

Both Mr and Mrs C described the financial stresses, for them of IVF [18], but only Mrs C perceived 'treatment failure as a personal failure' [14].

Box 3.1: Conceptual Categories for Couple C: Area One: the Experience of IVF	
b. Categories for the female participant	
[3] reasons for informing others	[14] blaming self for treatment failure
[6] expectations - helpful	[16] negative feelings engendered by health professionals
[7] expectations - unhelpful	[17] cautious responses of family members to treatment process
[10] lack of information - negative	
c. Categories for both participants	
[9] the negative effect of information	[18] financial stresses of treatment

Area two categories (Box 3.2) - Being told to stop treatment was experienced by couple C as a barrier to moving on [41]. With the category of 'unexplained' infertility as a negative factor [33] closely related to this, for Mr C,

"they couldn't tell us why, so we had nothing to focus on & to blame I suppose ... if we had a problem that we couldn't solve, then we could go on & say right we're not going to have any children lets go & do something else, but we can't do that" [33].

Both Mr and Mrs C found that they reacted quite dramatically to being told to stop treatment [42], with codes within this category including 'wanted to run away' and 'needed someone to talk to but not the news-giver'. They felt that only when they were able to decide for themselves and take control of their situation [19] were they fully able to move on,

"at that stage [after 2nd opinion] we decided that we just couldn't go any further with it, we'd gone as far as we felt comfortable with & although it was devastating we couldn't go any further ... I think we've explored the IVF & that hasn't worked so we've put that to bed, that's gone now" [43].

Mrs C experienced services severing their contact with her and her husband as abandonment [28],

"they'd just shut the door on us really ... we'd had all this intense involvement & then suddenly that was it, there was nothing ... nobody was doing anything anymore ... we'd just been left & I suppose you know, it just exploded in my head" [28].

She also 'felt that it would have helped if there had been someone professional to talk to' [29].

Box 3.2 Conceptual Categories for Couple C: Area Two the Decision to Stop	
a. Categories for the male participant [33] 'unexplained' infertility as a negative factor : : :	b. Categories for the female participant [22] difficulties in communicating [24] negative feelings once treatment has ended [28] abandonment [29] general areas in which support was lacking [38] having different coping styles - positive [39] having different coping styles - negative [40] general negative aspects of having the decision made for you [47] importance of time for oneself
c. Categories for both participants [19] taking control yourself of the situation [41] being told to stop - a barrier to moving on [43] general factors which made adjustment to stopping easier	
	[27] loss [42] reaction to being told to stop

Area three categories (Box 3.3) - Again, couple C were pursuing adoption as an alternative way of fulfilling the parenting role, and Mrs C appeared to take some comfort from this action

"it's giving us something to focus on, it's been our therapy really doing the adoption process, even if we don't follow it through right to the end it's going to help one way or another" [51].

Mr C, although committed to the adoption process, 'still believed that one day they would have a child of their own' [50]. Mrs C thought it had been useful to share experiences with others [56], and described the value to her of 'practical support from friends' [64]. She also believed that she had gained personally through IVF [57],

"I think as a couple we are a lot closer than maybe we were when we first started, I mean we've always been close but it's made us know each other even better" [57].

Box 3.3 Conceptual Categories for Couple C: Area Three Life Post Decision	
a. Categories for the male participant [48] positively re-framing life without children [50] the continued hope of natural conception	b. Categories for the female participant [51] adoption - positive aspects [52] adoption- negative aspects [54] views on egg/sperm donation [56] sharing experiences with others [57] personal gains of IVF [64] importance of friendships [67] current triggers to distress
c. Categories for both participants [63] receiving support from family	

5.2.5 Interview Four - Mr and Mrs D

Brief description of couple - Mr and Mrs D (aged 42 and 36 respectively) had been together for 15 years at the time of their interview. They had one son, aged 11, and

had been trying for a second child for nine years. Their first child was conceived naturally, and the origin of their secondary infertility was unexplained. Over a five year period they had two stimulated 'transport'¹ IVF treatment cycles, and one standard stimulated IVF cycle. Again, couple D were aware before their treatments commenced that they would receive NHS funding for three cycles. Following their final unsuccessful attempt, 12 months ago, they had made the decision to stop.

Reflections of the Researcher - Mrs D was experienced as rather cold and hostile. Her approach towards her husband was felt to be unsympathetic and attacking. She often called into question his thoughts and feelings, and placed him under pressure to explain himself. At times this made it difficult for him to respond perhaps as articulately as he would have liked.

Area one categories (Box 4.1) - Both Mr and Mrs D felt that they had not been provided with sufficient information about the IVF process to have enabled them to feel 'emotionally prepared' [10], although, Mrs D felt that she probably 'wouldn't have taken any notice if someone had tried to prepare her for disappointment' [9] anyway.

Mr D experienced his life as being on hold during the IVF [5]

"Everything goes on hold ... it seriously effects your relationships, your work, your social life, everything" [5].

He described feeling 'as though he were leading a double life' [2] because others were not informed of treatments. This seemed to add to the pressure he already felt to 'perform' and be successful [12].

¹ In 'transport' IVF the woman has the egg collection procedure at a hospital close to home. The eggs are then transported to an IVF clinic where they are fertilised then returned to the women.

Unsuccessful IVF was for this couple, their 'first experience of something going wrong in their life' [15] and as such they felt initially ill-equipped to deal with it,

"it was probably the first occasion when things didn't go right ... I think it was probably our first encounter with disappointment and that made it just difficult to cope with" [15].

Box 4.1 Conceptual Categories for Couple D: Area One the Experience of IVF	
a. Categories for the male participant	b. Categories for the female participant
[5] feeling that life on hold during IVF	[9] the negative effect of information
	[13] attributing external causes to treatment failure
c. Categories for both participants	
[2] not informing others of treatment - negative	[4] reasons for not informing others
[7] expectations - unhelpful	[10] lack of information - negative
[12] male partner feeling under pressure to 'perform' & be successful	[15] treatment failure disrupts 'life plans' of family

Area two categories (Box 4.2) - Mr and Mrs D did not agree about whether professional support was of value following the decision to stop treatment. Mrs D felt intervention was not necessary [31], whilst Mr D had accessed services and found them useful [30],

"I went to my doctor because I had trouble sleeping ... it started off like as anxiety but then was like depression and he prescribed prozac which was good & I had some counselling which really helped me sort myself out" [30].

Similarly, within their relationship Mr D 'coped by not talking about it' [25], whilst Mrs D stressed the importance of communication [20], with codes here including 'talking to each other alleviates friction' and 'talking has been the most helpful' [20].

Couple D thought that they coped more successfully with the decision to stop treatment because they had been 'told from the outset that they could only have three treatment attempts' [45]. Factors which seemed to make adjustment to stopping easier for them were identified as, 'realising for self that it's time to stop' and 'having a final appointment with the clinic for closure' [43],

"I think if you have the meeting it brings everything to a close, it's the final paragraph in the story if you want, which to us I think is quite important" [43].

For Mrs D, having secondary infertility was perceived as both a protective [35] and a negative factor [34]. She thought that 'already having a child made it easier to cope' [35] with their current situation, but she also described 'feeling as though she had let her son down' [34] because of her inability to produce a sibling.

Box 4.2 Conceptual Categories for Couple D: Area Two the Decision to Stop	
a. Categories for the male participant [24] negative feelings once treatment has ended [25] ways of coping [30] usefulness of formal services for support	b. Categories for the female participant [20] the importance of communication with partner [22] difficulties in communicating [26] sadness [31] no need for formal support services [34] secondary infertility as a negative factor [35] secondary infertility as a protective factor
c. Categories for both participants [19] taking control yourself of the situation [23] positive feelings once treatment has ended [43] General factors which made adjustment to stopping easier	
[44] stopping because of emotional strain [29] general areas in which support was lacking [45] helpfulness of being prepared for ending at the beginning of treatment	

Area three categories (Box 4.3) - Life post-decision highlighted for couple D that they now had no further options available to them [53 & 54]; Mrs D was 'hanging onto the glimmer of hope' of natural conception [50]. but they were both trying to positively re-frame their life without another child [48],

"we should be grateful for what we've got ... try and enjoy what we've got get on with life, the house, holidays, & son's activities" [48].

They felt that things had been made more difficult for them by the negative responses of others [59], with codes here including 'others don't understand' 'insensitivity of people saying well at least you've got one' and 'pitying responses of others'. Not all their experiences with other people were, however, negative. They both found it 'supportive talking to like others' and agreed about the helpfulness of meeting with others in a similar position [56].

Box 4.3 Conceptual Categories for Couple D: Area Three Life Post Decision	
a. Categories for the male participant [54] views on egg/sperm donation [55] feeling resigned to one's lot in life [57] personal gains of IVF	b. Categories for the female participant [50] the continued hope of natural conception [53] adoption neutral
c. Categories for both participants [48] positively re-framing life without children [59] negative responses of others	
[56] sharing experiences with others	

5.2.6 Interview Five - Mrs E

Brief description of individual - Mrs E (aged 37) was the only one of the eleven participants who took part alone; her partner wished not to be interviewed. She and her partner had been together for 12 years and they had a six year old son. They had been trying for a second child for four years, but had been unsuccessful because Mrs E had a blocked left fallopian tube, and a damaged right ovary. At the time of her interview, she had undergone one stimulated IVF treatment cycle, funded by the NHS. The ACU had made the decision to stop treatment 5 months ago, because three good quality embryos were not produced.

Reflections of the Researcher - Mrs E appeared rather an isolated, deeply sorrowful woman. She gave the impression of being unsupported by both her family and partner, and seemed to value the opportunity, through the interview, to express, and have her feelings acknowledged by another.

Area one categories (Box 5.1) - Mrs E thought that her initial 'pessimism about treatment outcome' [6] had helped her manage the disappointment when it was not successful. By not informing others of her treatment, she also thought that she had been able to protect herself from the potential disapproval of others,

"a lot of people knew that I was desperate to try & have a baby but not all of them knew that I was going through the IVF because I just think it is so very personal ... I didn't want to talk to them about it because in a way I was afraid that they would say no, no, no don't do it" [4].

Box 5.1 Conceptual Categories for Individual E: Area One the Experience of IVF

- [4] reasons for not informing others
- [6] expectations - helpful
- [8] ambivalence
- [9] the negative effect of information

Area two categories (Box 5.2) - Stopping treatment was extremely difficult for Mrs E, clearly exacerbated by the fact that the origin of her infertility was 'explained' and lay primarily with her [36],

"probably because the problems are all me I find it harder ... I think I feel angry, angry with myself, why should I be having problems?" [36].

Mrs E also thought that she found it 'harder to accept her infertility' because it was secondary in nature [34],

"both of us find it hard to accept that we can't have another one ... the fact that we did it before, I just find it hard to think that I can't have another one this time" [34].

She described 'feelings of hopelessness' [24] when treatment ended, feeling that nothing now was going to work for her. She coped by putting on a facade, 'pretending that everything was all right' [25], merely because she 'found it difficult talking to her husband when she needed to' [22].

Mrs E thought formal support services had been useful for her [30], although there were several general areas in which she felt support was lacking [29]. Codes within this category included 'not wanting to feel so alone' and 'talking to others in a similar situation would have helped the healing process'. She had 'felt unable to attend support groups for fear of offending others because she already has a child', which thus restricted her supportive opportunities [34].

Box 5.2 Conceptual Categories for Individual E: Area Two the Decision to Stop

- | | |
|---|---|
| [19] taking control yourself of the situation | [21] feeling unsupported by partner |
| [22] difficulties in communicating | [24] negative feelings once treatment has ended |
| [25] ways of coping | [29] general area in which support was lacking |
| [30] usefulness of formal services for support | [34] secondary infertility as a negative factor |
| [36] 'explained' infertility as a negative factor | [37] having different coping styles - neutral |
| [40] general negative aspects of having the decision made for you | |

Area three categories (Box 5.3) - Mrs E described 'continually thinking about having another child', stating that she was 'not ready to give up trying' for a baby [50]. She felt that 'life just was not fair' [61] and found that her feelings towards those with children had at times been quite hostile,

"sometimes I go shopping & see a woman & I am so jealous, I can't take my eyes off her, I just keep looking at her bump & think this is what I want to have... I feel angry, it's not rational but I feel angry" [60].

She felt that life post-decision had been made more difficult for her because of the negative responses of others [59], and the negative impact of society [62]. Codes within this latter category included 'finding life around children punishing' and 'feeling that there's no getting away from reminders of children',

"others don't understand ... it really didn't help when people would say well you've already got one child just concentrate on that one cos I mean having one child in some ways makes it even more difficult to cope because you have already experienced what it's like to be pregnant, have that baby and I just find it very, very hard" [59 & 34].

Box 5.3 Conceptual Categories for Individual E: Area Three Life Post-Decision

[50] the continued hope of natural conception	[53] adoption - neutral
[57] personal gains of IVF	[59] negative responses of others
[60] feelings towards those with children	[61] the 'unjustness' of the world
[62] the negative impact of society	

5.2.7 Interview Six - Mr and Mrs F

Brief description of couple - at the time of their interview, Mr and Mrs F (aged 36 & 39 respectively) had been together for 10 years. They had been trying to conceive for four years and had received no explanation for their infertility. Over an eighteen month period they had undergone one stimulated IVF treatment cycle and one ICSI cycle, both funded by the NHS. Prior to treatment they had made the decision themselves to have just two IVF attempts, and consequently stopped treatment eighteen months ago.

Reflections of the Researcher - Although Mr F was more vocal during the interview, Mrs F seemed more comfortable than he when expressing her feelings about IVF and the decision to stop. His 'matter of fact' approach was felt by the Researcher to be a defensive strategy, employed for self-protection, so he could avoid experiencing the full extent of his distress.

Area one categories (Box 6.1) - Couple F both thought that not informing others of their treatment had been a positive step on their part [1] as they found it easier just to cope with their own disappointment. However, Mrs F did 'feel that perhaps not telling others was selfish and minimised support to be gained' [2]. Mr F felt that having expectations of treatment played both a helpful and unhelpful role in managing his disappointments during IVF,

"[the clinic] were very up front about the chances of success, they were not in anyway deluding us & they were not in anyway raising false expectations, which I thought was a very responsible thing to do" [6].

And he felt that because of the importance for them in having a child, IVF had at the time, unhelpfully 'become the focus of their life' [5].

Box 6.1 Conceptual Categories for Couple F - Area One the Experience of IVF	
a. Categories for the male participant [5] feeling that life on hold during IVF [6] expectations - helpful [7] expectations - unhelpful [15] treatment failure disrupts 'life plans' of family	b. Categories for the female participant [2] not informing others of treatment - negative [13] attributing external causes to treatment failure
c. Categories for both participants [1] not informing others of treatment - positive	

Area two categories Box 6.2) - Couple F's comments regarding their decision to stop treatment were generally positive. They found that taking control yourself of the situation helped, with codes here including 'having a plan of action to deal with the situation' and making the decision at the beginning to only have 2 attempts' [32].

Similarly, Mr F felt that it helped not knowing whether it was him or his wife, with whom the fertility problem lay,

"I actually have to say I think it helped an awful lot not knowing, if both of you have got a problem then you don't think that someone else is to blame, that your partner is blaming you. So I think we were quite lucky because we still don't really know it's unexplained" [32].

Both Mr and Mrs F emphasised the importance for them of communicating with each other [20],

"I think one of the main things is that we talked quite openly about it all to each other, so we've always had each other for support. We never really argued about anything, we seemed to both come to the same conclusions at similar times really" [20].

And both described 'feeling relieved when treatment ended' [23]. Mrs F also indicated that she had gained support from outside the relationship [30] and that she 'felt that it would have been nice to meet with other people and share experiences' [29],

"I suppose at the end it would probably have been quite nice to meet other people to find out what their experiences were and have a bit of a session so you don't feel so alone" [29].

Box 6.2 Conceptual Categories for Couple F - Area Two the Decision to Stop	
a. Categories for the male participant [32] 'unexplained' infertility as a positive factor	b. Categories for the female participant [29] general areas in which support was lacking [30] usefulness of formal services for support
c. Categories for both participants	
[19] taking control yourself of the situation [23] positive feelings once treatment has ended	[20] the importance of communication with partner

Area three categories (Box 6.3) - Life post-decision for couple F, had been largely taken up with their pursuit for a child through the adoption process. Their experiences here had been both positive [51] and negative [52], but overall they appeared to be using the adoption process to help them manage the disappointment of IVF,

"the adoption process has been a real kind of ... it's helped, it's almost like we've been able to put it [the IVF] out of our minds now. It has been a good thing to do because again it helped us to focus, it helps you to live with your disappointments and makes it a lot better" [51].

Mr F's approach to life without biological children was very 'philosophical', he 'felt that there was more to life than children' [48], and that 'those with children should

appreciate just how lucky they are' [60]. For Mrs F, however, the continued hope of natural conception was an important category [50].

Box 6.3 Conceptual Categories for Couple F: Area Three Life Post-Decision	
a. Categories for the male participant [48] positively re-framing life without children [54] views on egg/sperm donation [57] personal gains of IVF [60] feelings towards those with children	b. Categories for the female participant [50] the continued hope of natural conception
c. Categories for both participants [51] adoption - positive aspects [58] positive responses of others	
[52] adoption - negative aspects	

5.2.8 Thematic Analysis

Individual codes were rarely literally repeated by participants, but meaning was shared by many. Box 7.1 describes the categories which occurred consistently across interviews, that is those which were mentioned by five, or more participants (the numbers in brackets following each category refer to the number of participants who gave responses here).

Box 7.1 Categories Occurring Consistently Across Interviews	
[3] expectations - helpful (5)	[23] positive feelings once treatment had ended (6)
[7] expectations - unhelpful (6)	[24] negative feelings once treatment had ended (6)
[10] lack of information - negative (5)	[25] ways of coping (5)
[19] taking control yourself of the situation (8)	[29] general areas in which support was lacking (6)
[20] the importance of communication with partner (6)	[48] positively re-framing life without children (8)
	[50] the continued hope of natural conception (7)

Differences between male and female participants were also rare. Box 7.2 describes those categories which were mentioned only by female participants, with difficulties in communicating [22], and adoption - neutral [53] consistently referred to by four female participants. Categories predominantly mentioned by male participants included feeling that life on hold during IVF [5] (3 males:1 female), and positively re-framing life without children [48] (5 males:3 females). The category of 'unexplained' infertility as a positive factor [32] was similarly mentioned by only one male participant.

Box 7.2 - Categories for Female Participants Only

[3] reasons for informing others (1)	[37] having different coping styles - neutral (1)
[8] ambivalence (1)	[38] having different coping styles - positive (2)
[11] general issues about information (1)	[39] having different coping styles - negative (1)
[13] attributing external causes to treatment failure (2)	[40] general negative aspects of having the decision to stop made for you (2)
[14] blaming self for treatment failure (2)	[49] constructing an identity for self without children (1)
[17] cautious responses of family members to treatment process (1)	[53] adoption - neutral (4)
[21] feeling unsupported by partner (1)	[62] the negative impact of society (1)
[22] difficulties in communicating (4)	[64] the importance of friendships (1)
[26] sadness (1)	[66] availability of technology makes adjustment difficult (1)
[34] secondary infertility as a negative factor (2)	[67] current triggers to distress (2)
[35] secondary infertility as a protective factor (1)	
[36] explained infertility as a negative factor (1)	

Through a continued analysis of the codes and categories generated the following five core themes were identified as unifying the data:

i) Issues of control

Control was a central theme which emerged throughout the data. The extent to which participants perceived themselves to be in control of their feelings and their treatment decision making, seemed to play an important role in their coping response.

Having realistic expectations about the likelihood of treatment success, seemed to facilitate participants in managing difficult feelings following treatment failure and the decision to stop. Some participants felt unprepared and uninformed about IVF and perceived that more information would have been helpful. Information would have allowed them to prepare for disappointments, as well as enabling them to feel more in control of their situation.

Experiencing problems with fertility was for some, their first encounter with a 'life crisis', the outcome of which was out of their control. Participants who took active steps to regain a degree of control and sense of mastery over their treatment decision

making, for example, those who set a limit on the number of treatment cycles prior to the commencement of treatment, found that they were helped to accept the ending of treatment when it arrived. Being prepared, at the beginning of the process for treatment ending was therefore seen as a positive pro-active strategy. Similarly, participants who were able to make the decision to end treatment themselves, thereby re-claiming control from health professionals, found that they were able to stop and move forward from treatment more easily.

ii) *Interpersonal resources and the personal construction of treatment failure*

The perceived quality of participants' marital relationships did seem to influence the course of adjustment and coping following the decision to discontinue IVF (*research question vii*). Participants who felt supported by their partners perceived this to have had a positive effect on outcome for them. Conversely, feeling unsupported by one's partner was linked to increased difficulties with coping, and more pronounced feelings of isolation and hopelessness.

Communication within the dyad was indicated by participants to be of major importance in assisting them in managing IVF and the decision to stop. Some difficulties in communicating within relationships were reported by female participants, seeming to arise chiefly because of opposing styles of coping. Male participants seemed to engage in more avoidant, 'solo' ways of coping, whilst female participants were more likely to value 'expressive acts', such as sharing experiences with others, and having friends to talk to.

Treatment failure was constructed in one of two ways by female participants, either attributable to external or internal factors (*research question ii*). Attributing treatment failure to external causes, to factors beyond their control, was perceived by the Researcher as being the more adaptive strategy to employ. Blaming oneself, and perceiving treatment failure as a personal failure seemed less helpful. Those employing this latter strategy seemed to experience more intense feelings of disappointment and devastation following the discontinuation of treatment.

iii) Beliefs about one's infertility and the treatment decision making process

Participants' beliefs about the origin of their infertility seemed to play an important role in influencing the ease with which they were able to accept the termination of treatment.

A diagnosis of 'unexplained' infertility prevented some participants from moving on successfully. Not knowing the origin of one's infertility was perceived as being an ambiguous position to occupy, with those affected feeling both helpless and frustrated. Participants believed that because they had nothing 'concrete' to focus on, they could neither take active steps to resolve the problem, nor could they accept it and move forward in life. However, in contrast one participant did speak favourably about having no explanation for the infertility. He believed that because sole blame for the problem could not be attributed to either himself or his partner, tension and dissatisfaction within the relationship was avoided. The one female participant whose infertility was 'explained', believed that knowing the problem lay with her, had made it harder for her to cope once treatment had ended. Similarly, secondary infertility was not consistently seen as 'protecting' one's well-being following IVF termination.

The manner in which the decision to discontinue IVF originated, did seem to affect participants perceived ability to adjust (*research question i*). Deciding for oneself was perceived as a positive factor, which facilitated the process of participants' adjustment. Conversely, being told to stop was perceived as impeding the activation of this adjustment process. Participants having the decision to stop made for them, seemed neither cognitively nor emotionally prepared to accept this enforced ending to their treatment; one couple were only fully able to abandon the idea of IVF when they could accept for themselves that no other option was available to them.

Although the financial strain of IVF was indicated by some participants to have played a role in their decision to stop treatment, this was never identified as the single most important influencing factor in the decision making process.

iv) External support and the relationship with infertility services

Participants' networks of social support seemed to play a vital role in their perceived level of adjustment (*research question iv*). Those participants who decided not to tell others about their IVF found that this limited their opportunities for support, and increased their sense of social isolation. Interactions with friends and family were seen as both helpful and unhelpful, with some participants able to gain practical and emotional support from friends, whilst others felt overwhelmed and misunderstood.

Intervention from primary care counselling services was perceived by those participants with secondary infertility as having helped them adjust to life following IVF termination. These participants also perceived themselves to be isolated from certain support structures available within the 'infertile community', namely support

groups. Participants with primary infertility accessed neither clinic nor outside therapeutic services, although some believed that this would have been helpful. Participants felt that having the opportunity to speak with an impartial professional in the crucial period immediately after the decision to stop treatment, would have assisted them to begin coping in more functional ways (*research question iii*).

Most participants indicated some dissatisfaction with the level of follow-up offered by the infertility service. Some couples felt abandoned by the clinic, and perceived the abruptness with which services stopped as contributing to the difficulties they encountered in adjusting to life following IVF. One couple who did attend for follow-up, highlighted the importance of this to them in terms of achieving an overall 'closure' to the treatment process.

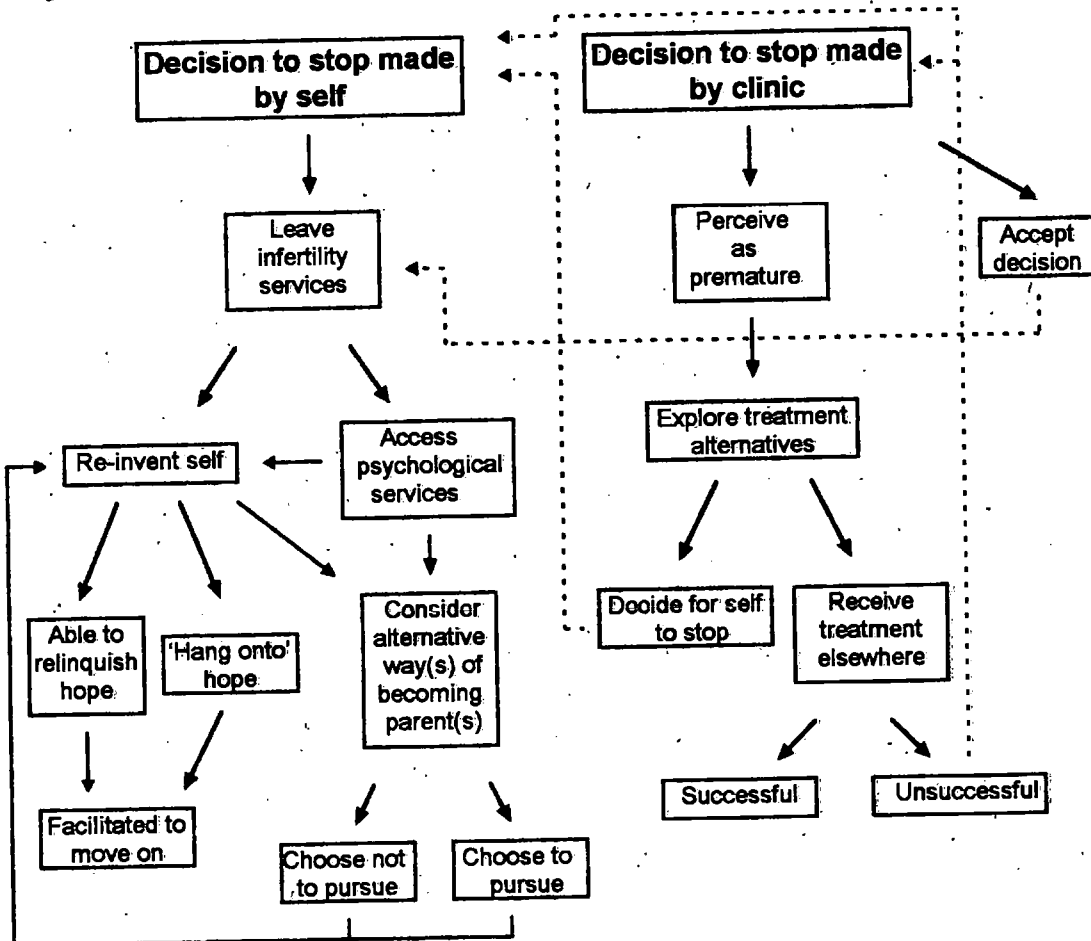
v) *Alternative ways to fulfil the parenting role (research question vi)*

Most participants described their ability to construct, and re-frame a life for themselves without children as helping them adjust to treatment stopping. However, few participants had actually given up hope of conceiving naturally, and all but one of the couples with primary infertility were attempting to fulfil their desire for a child by pursuing the adoption process. Some couples explicitly stated that they were using their involvement in the adoption process to help them manage the disappointment of the IVF. Whilst others saw it not as a cure for their failed IVF attempts but more as a way of 're-evaluating life'. Unlike those with primary infertility, participants with secondary infertility felt that because they had already experienced the pleasure of parenting a biological child, adoption was not a feasible option for them.

5.2.9 A Summary

The data and themes presented within this section are further represented within the following pathways model, showing the points of choice and decision making encountered by individuals stopping IVF.

Figure 1 Pathways model showing the outcomes of self-imposed and externally-imposed decisions to stop IVF treatment



Rebecca Smith BSc Hons

**Infertility: A Quantitative Report of Clinical Psychologists'
Therapeutic Contact with Sub-Fertility Clients, and a Qualitative
Analysis of the Experience of these Clients' and Their Subsequent
Psychological Adjustment, Following the Discontinuation of In Vitro
Fertilisation Treatment.**

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the degree of Doctor in Clinical Psychology

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6. Discussion

6.1 Outline

The following points will be included within this discussion:

- i) an evaluation of the two research methodologies employed within the investigation
- ii) an exploration of the findings of the quantitative section of the investigation
- iii) the proposing of a tentative theoretical framework, grounded in the data and themes presented within *results section 5.2*, to explain the experience and adjustment of individuals who have discontinued IVF treatment
- iv) a discussion of the implications of the findings for clinical practice and recommendations for future research in this area.

6.2 Evaluating the Quantitative Methodology (Section One)

The survey design employed was appropriate for this section of the current investigation as it enabled a large proportion of UK Clinical Psychologists to be approached to participate. Given the good response rate achieved for the survey, its findings can be accepted with some certainty as reflecting a representative view of Clinical Psychologists who work with people with fertility problems.

The conciseness of the survey instrument was believed to play a significant role in obtaining the good response rate from participants. Many participants expressed their appreciation to the Researcher for the 'true' brevity of the survey, indicating that this had influenced their decision to participate. Similarly, the good response rate seemed to indicate that the topic was of relevance to participants' clinical practice.

The survey instrument did, however, contain one identifiable flaw. A small number of participants stated that they had only worked with *one* individual with a fertility problem. They were thus unable to complete the ranking required within the questions exploring *reasons for referral* and *therapeutic tasks*. Whilst these participants were able to overcome this difficulty by assigning the rank of one (most common) to the reason for referral, and therapeutic task which described their contact with their single client, with hindsight, adding a statement instructing participants to do this may have promoted clarity.

6.3 Evaluating the Qualitative Methodology (Section Two)

6.3.1 *The generalisability of findings*

Claims of 'representativeness' cannot be made within qualitative research as the methodology only embraces a small number of participants. Instead depth of understanding, in a particular area, is the aim of such methodologies (Silverman, 1993).

The sample for this investigation were chosen from the pool of individuals who had stopped IVF treatment at one hospital. Only a limited selection criteria was laid down to enable as representative a cohort of individuals to be accessed as possible. Although the sample achieved did seem to reflect a cross-section of this population, Henwood & Pidgeon, (1995) have suggested that such limited samples raise questions about the generalisability of findings.

Only those individuals who were known by the clinic to have stopped treatment were approached to participate in this current study. It may have been anticipated, therefore, that individuals told by the clinic to stop treatment, would constitute a larger proportion of the

pool of potential participants; this however, was not the case. Unquestionably though, there may have been some individuals who had stopped treatment about which the clinic had no knowledge, and therefore could not be approached to participate. Perhaps these individuals were coping in a different way. Does not informing the clinic represent a positive or negative coping style?

The sample, additionally, contained only participants who volunteered to take part and this may have led to a biased sample, as it is possible that only those who perceived themselves to be coping well volunteered to participate. Whilst this was always recognised as a possibility by the Researcher, it was not a cause for concern as the investigation was primarily interested in the process of coping, not its success. (Individuals who did agree to participate did, however, reflect a range of 'successful' coping). Similarly, it could be argued that individuals' reasons for agreeing to participate may have skewed the sample in a particular direction; again this was not borne out by the data. Some participants viewed the interview as a cathartic opportunity, whilst others expressed more altruistic motives.

To summarise then, the clinical and demographic variables within the current sample suggest it may be representative of the population of people stopping IVF treatment, however, because of the self-selection bias this can only be cautiously accepted.

6.3.2 *Reliability and validity*

Reflexivity and auditability

It is argued, that one way of evaluating research is to explore the extent to which the researcher has *reflected* upon the research process; in this sense, 'good' psychological

research requires the researcher to actively consider whether their involvement in the process has enhanced or detracted from the research findings (Stevenson & Cooper, 1997). Within the current research, an attempt was made to make explicit the Researcher's understandings, interpretations and personal reactions to the data, to enable the reader to scrutinise the research process and to develop their own interpretations and explanations.

An 'audit trail' (Lincoln & Guba, 1985) was set up to facilitate this which included:

- the keeping of a reflexive research diary throughout the course of the research process (this is open to external audit - Appendix 9).
- detailing all steps of the data collection and process of analysis, including a full description of all the codes and categories generated (Appendix 10).
- documenting, within the Introduction, the Researcher's ideas about the issues of relevance in the area, which informed the development of the research questions, and the areas explored within interviews.

Inter-rater reliability

An independent rater was used to judge the reliability of the Researcher's categorisation and coding (Appendix 8). The percentage agreement between the Researcher and the Independent Rater was good throughout. The findings of the inter-rater reliability study could have been strengthened still further had a Cohen's kappa formula (Cohen, 1960) been used to control for chance agreement between raters. The procedure employed within this inter-rater reliability study did, however, not lend itself to this analysis. To have expected the Independent Rater to have considered *all* codes and categories generated for the two interviews being studied (a total of 65 basic

codes & 35 categories) was judged by the Researcher and Supervisor to be an unreasonable demand.

Respondent validity

The Researcher is aware that other means could have been employed to ensure rigour within this investigation, for example *Respondent validity*. Within grounded theory the criterion of 'respondent validation' has been employed to determine the degree to which researcher's findings represent their participants realities (Pigeon, 1996).

A number of practical and theoretical reasons are proposed to explain why a study of respondent validity was not carried out. First, difficulties initially encountered in the recruiting of a sample (see dissertation diary - Appendix 9), meant that time for data collection and analysis was limited. Whilst the Researcher did feed back the typed transcripts to participants in an attempt to validate the findings, feeding back the emerging analysis was not practically possible. Second, some debate does exist within the literature regarding the suitability of respondent validity as a method of assessing validity (Henwood & Pigeon, 1995). Do participants feel truly able to challenge the researcher's interpretations if they perceive the researcher as an 'expert' in the field? Similarly, do participants always fully understand the context of the research? Consequently, any results obtained from such a study would have had to be treated with some caution and therefore, the Researcher believed the decision not to complete was most appropriate.

6.4 The Findings of the Survey of Clinical Psychologists

6.4.1 *The amount and type of referrals received by Clinical Psychologists for individuals with fertility problems*

Overall, the results of the survey of Clinical Psychologists indicate that only a small proportion of the profession are actually working therapeutically with individuals who have fertility problems. Predictably, most such clients are reported to have been seen by Clinical Psychologists attached to specialist infertility services. Also, Clinical Psychologists working in 'front-line' primary care services and other health psychology settings are more likely to have had contact with these clients than those in other specialisms.

Given what is known about the incidence of fertility problems within the population as a whole (affecting approximately 15 per cent of couples), and the impact of infertility on emotional and psychological well-being (Pfeffer & Woollett, 1983) it is perhaps surprising, that the reported formal contact with this client group is so small.

Clearly, not everyone affected will require psychological input, so estimating the exact level of service requirement for this client group is difficult. However, this low uptake of services by people with fertility problems, is startling when one considers that problems of anxiety and depression (which as noted by Clark, 1989, and Champion, 1992, affect only between three and seven per cent of the population) constitute the majority of work conducted by Clinical Psychologists in adult services. Therefore, one may ask why it is that so few Clinical Psychologists are seeing individuals with fertility problems?

One possible explanation is that the problem originates with professionals who make the initial referral decisions. The current survey showed that referrals made to Clinical Psychologists rarely stated infertility as the primary reason for referral and in some cases infertility was not mentioned at all. By contrast, Clinical Psychologists regarded dealing with the issue of infertility as one of the most important tasks for therapy. This shows a conceptual gap between referrers' and Clinical Psychologists' perception of the problem of infertility. This may be explained in a number of ways:

- referrers may not have the skills, or feel confident enough to identify infertility as the primary problem,
- referrers may not perceive fertility problems as acceptable reasons for requesting psychological input,
- individuals may present to referrers with 'other' problems, because they perceive this to be the only way for them to receive help.

6.4.2 Clients with fertility problems who received Clinical Psychology services

The survey showed that individuals who had already received medical intervention for their fertility problems made more use of Clinical Psychology services than individuals who had received no treatment. Three reasons are proposed to account for this. First, those receiving treatment have already demonstrated their inclination toward using active strategies to manage difficulties. Thus, seeking help from a Clinical Psychologist may constitute just another *active* coping strategy by which to deal with their infertility. Second, the affect of the physical intervention of infertility treatment may in itself mean that individuals become susceptible to mental health difficulties, and thus may require psychological intervention to manage this. (This is illustrated by a

recent survey of 1,300 individuals who had treatment, in which nearly half had experienced depression, and one in 20 had felt suicidal; Moreton, 1998). Finally, accessing help may be easier for those who have received treatment, simply because they already perceive themselves to be part of the 'service culture'. Overall, these results suggest that there may be an area of unmet psychological need in relation to individuals who decide not to undergo treatment for their infertility.

The majority of clients seen by the Clinical Psychologists completing the survey, were females or couples. Some contact with lone male clients was reported by Clinical Psychologists working in non-specialist infertility settings (e.g. primary care), however, men generally accessed services only when they presented as part of a couple. This finding seems to reflect a stark gender imbalance, which raises questions about whether current service provision is accessible to all. (This will be discussed in more detail within the clinical implications section of this discussion).

6.4.3 Contact with clients who had decided to discontinue infertility treatment

Clinical Psychologists working in private practice and older adult services reported the most contact with this sub-group of clients. Two possible reasons are proposed to account for this. First, the stigma attached to infertility treatment and failure, may lead clients to seek private psychological help in order to avoid the potential exposure of mainstream services. Similarly, as mentioned previously, referrers may not perceive adjustment difficulties following the termination of IVF, as a problem worthy of NHS resources. Second, in the older adult phase of life, difficulties often emerge as a result of 'life reviews', in which unresolved issues from the past re-emerge (Erikson, Erikson & Kivnick, 1986). Individuals therefore, who have been unable to adjust to their

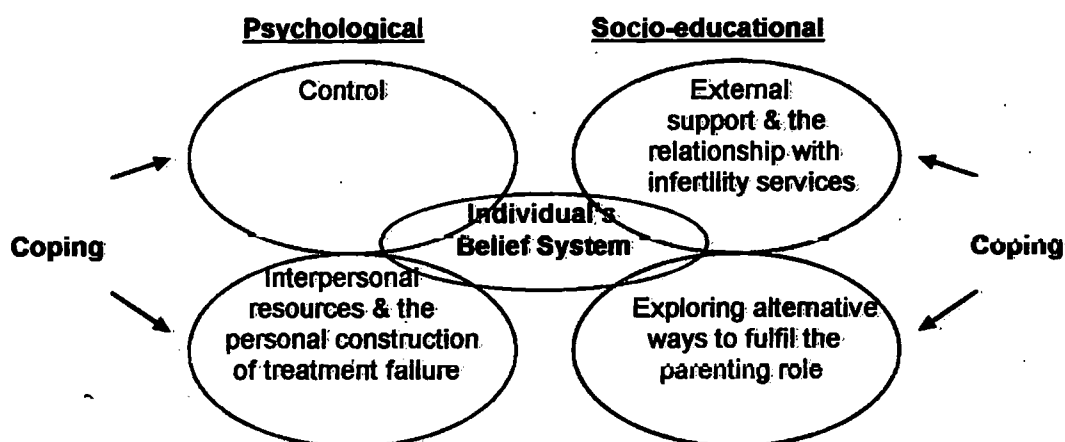
childless status following the discontinuation of infertility treatment earlier in life, may find that this precipitates difficulties within 'old age', which require the intervention of services.

6.5 The Experience and Adjustment of Individuals who have Discontinued IVF Treatment - Approaching A Theoretical Framework

Of the seven research questions initially proposed, all but one (*research question v*) emerged as important factors in relation to individuals' perceived levels of adjustment and coping.

The factors identified in the current study can be split into three areas, (a) psychological factors, (b) socio-educational factors and (c) the individual's belief system, and can collectively be drawn together to form a preliminary process model to explain the experience of individuals who discontinue IVF treatment. These factors or '*dimensions of adjustment*' seem to fall along a conceptual continuum, with psychological factors at one end and socio-educational factors at the other, with the individual's belief system forming a mid point around which the other two interact. This is demonstrated by the following diagram;

Figure 2 The Dimensions of Adjustment



Within this model, adjustment is seen as a dynamic process, with the factors representing the coping strategies individuals employ to help them manage the process of ending treatment.

In themselves, the psychological and social factors presented are suggested to have the potential to lead to greater or lesser adaptation for individuals who discontinue IVF. However, it is tentatively proposed that the effects of these factors are mediated by a core process within the individual, that is their belief system. For example, two individuals may have equally supportive partners and may both have decided to only have two IVF attempts, however, following the termination of treatment their levels of perceived adjustment may be different. It is suggested that this may occur because each individual's interpretations of the psychological and social factors, and their beliefs about the experience, are qualitatively very different.

(a) Psychological factors

(i) *Control* - one of the most important themes that emerged as influencing levels of adjustment and coping was the degree of control participants' felt they had over the decision to end treatment. In this sense, participants' perception of 'self' emerged as an important coping mechanism. Those who believed themselves to be controlled by outside forces, that is their locus of control was *externally* oriented, were less likely to engage in positive coping behaviours and experienced feelings of reduced self-efficacy. Conversely, those who believed that they had the ability to influence and determine facets of life, that is they had an *internal* locus of control, seemed more likely to act for themselves to facilitate their coping and adjustment.

For participants, recognising that IVF treatment and its failure might engender feelings of helplessness, facilitated the employment of a variety of active coping strategies to prepare themselves, such as seeking information, formulating realistic expectations, and setting a limit for the number of treatments. This enabled participants to moderate their stress and manage the process of ending treatment more effectively. **In short, individuals who feel in control of their feelings and the treatment decision making process, seem to have the potential for greater adjustment.**

(ii) Interpersonal resources - participants who perceived themselves to be in a satisfying, mutually supportive and complimentary relationship with their partner, identified this as influencing the course of adjustment and coping following the decision to stop treatment. Whilst such a psycho-social environment did not 'buffer' individuals from the distress and disappointment of IVF, it did seem to impact on the course, and speed with which a positive outcome could be attained. **Therefore, quality of the spouse relationship has the potential to predict how well individuals will manage the decision to stop treatment.**

The attributions that people make to explain or understand events within their lives, have been found to impact on their level of psychological well-being (Abramson, Seligman & Teasdale, 1978). This was borne out within the current sample. The ability to attribute treatment failure to transient, specific, and external causes seemed to serve a protective function for participants. Those, however, who attributed failure to their own personal inadequacies were more exposed to their disappointment. Here, feelings of hopelessness and helplessness were thus maintained and adjustment made more difficult. **Therefore, it seems that whether a individual attributes treatment**

failure to themselves or external events has the potential to predict the level of adjustment that they will make.

(b) Socio-educational factors

(i) *External support and the relationship with infertility services* - social support is known only to be effective when an individual's interpersonal relationships provide the resources that fulfil the coping requirements of a particular stressful event (Niven, 1989). For participants within the current sample, social support, (namely relationships with family and friends) was perceived as being both helpful and unhelpful. Participants who were able to receive gains, both practically and emotionally from their interactions with others felt that this facilitated coping. Whilst interactions with critical and 'ignorant' friends was perceived negatively. In short then, it appears that the quality of the individuals perceived interpersonal relationships, rather than the quantity of their social network, is potentially predictive of effective coping.

Secondary infertility was not identified within the current studies as buffering individuals from the harmful consequences of their infertility. Participants with secondary infertility perceived their adjustment to have been more problematic because they had already experienced the pleasure of bearing and parenting a child. Two out of three of the individuals who already had a child sought external support from therapy services, to assist them with their coping. In short, having a child seems to expose people to a greater sense of disappointment and loss, rather than actually buffering them from the distress of their infertility.

Contact with infertility services, or more specifically lack of contact, was identified by participants as negatively impacting on their ability to cope once treatment ended. This suggests therefore, that perceiving that the infertility clinic cares about your well-being (even though you may no longer be receiving treatment) is an important factor which may help one to adjust and cope more successfully.

(ii) *Exploring alternative ways to fulfil the parenting role* - within the current sample, most participants were attempting to develop a positive view of childlessness through constructing and re-framing a life for themselves without children. This was perceived by the Researcher to signify an important first step, taken by couples, toward establishing identities for themselves as individuals without children. However, few participants had actually given up hope of conceiving naturally, and many were attempting to adopt a child. It is suggested therefore, that whilst couples within the sample may have adjusted to treatment ending, they had not as yet reached a stage where they could accept their childlessness. It can be queried then, whether individuals ever reach such a stage of resolution of their infertility, and if so, what are the different processes which must be resolved to enable individuals to achieve this?

The fact that couples within the current sample, had not looked to other ways to validate themselves, such as through their careers or through the taking up of new hobbies and interests, again seems to confirm that they were at an early stage within their adjustment to childlessness. Most couples, with primary infertility, still sought to validate themselves through becoming parents and adopting a child.

(c) The individuals belief system

The specific origin of participants' infertility was not consistently reported as influencing adjustment, either positively or negatively. Whilst for some participants, having an 'unexplained' origin to their infertility inhibited successful coping, for others it was perceived positively, in that blame could not rest with either part of the dyad. Similarly, neither knowing the origin of the one's fertility problem nor already having a child were seen as 'protective' of well-being, following treatment termination.

It seems impossible, therefore, to identify one single statement about the type of belief (relating to origin of the infertility) that will be most helpful or unhelpful for individuals to hold when ending IVF. **Instead findings of the current study suggest that individuals make sense of things in very different ways, and that it is the meanings that are attributed to beliefs, rather than the beliefs themselves, which emerge as important.**

Individuals seemed to believe one of two things about why their treatment stopped. Either that it stopped because they wanted it to stop, or that it stopped because they were made to stop. Decisions made by couples themselves, were perceived as facilitating the process of adjustment whilst being told to stop seemed to inhibit this process. Participants believing the decision to stop had been made prematurely by the infertility service were unable to accept and thus move on, until they could reach an understanding themselves that this was the appropriate course of action.

As previously mentioned, all the factors described above can be understood as individuals' mechanisms for coping. No one coping strategy 'stood out' within the

sample as being consistently more helpful than another, when adjusting to life after IVF. What seemed more important was the ability to be *flexible* in one's coping. This pre-supposes, however, that individuals can identify when a strategy has out-lived its usefulness, and raises questions about some of the strategies that participants were currently employing. For example, 'hanging onto' the hope of natural conception, whilst identified as helpful by participants, may only be so in the short term. Individuals are likely to become 'stuck' if they continue to utilise such a strategy when it is no longer appropriate.

The issues which seemed not to be significant to the process of individuals adjustment are now briefly explored.

(i) The course of treatment and point at which it fails

Across the sample, the number of unsuccessful IVF attempts varied, however, no couple identified the amount of treatment (no. of cycles) that they had received as having any bearing on their ability to cope once treatment had ended. Of the three individuals who had only one attempt, all identified the manner in which they were told to stop as the more salient factor. This suggests that, the level of emotional investment participants make in the IVF process is of more importance than the level of 'practical' investment (e.g. money, time, etc.).

All the couples interviewed experienced treatment failure at a similar stage, that is their embryos failed to implant following transfer. Couples again, did not identify this as a major factor influencing their level of adjustment. This finding should, however, be looked at within the context of the current sample, as there are couples receiving treatment who fail at other stages, for example, those who miscarry. Would the point

of failure have been more relevant to this group? Did this group make the conscious decision not to participate in the study, if so why?

Considering what is known about the emotional and psychological distress experienced by women who miscarry (Conway, 1995). It is possible that for individuals who miscarry following IVF, being 'closer' to their goal and experiencing a real as opposed to imagined loss impacts in some way on their level of adjustment and coping once the decision to stop is made.

Age and gender

Neither gender nor age emerged as an important factor in predicting the level of individuals' perceived adjustment and coping. These findings are revealing, but again, may have occurred because of sample bias. Age may have been seen as an influencing factor if it had precipitated the decision to stop (a possibility given that NHS treatment is often refused to female patients over 40). Likewise, differences between the sexes may have been highlighted if couples had been interviewed separately. This may have reduced the pressure for some participants to 'conform' with partners. Alternatively, however, some may have been less likely to volunteer to participate if they had been denied the support of their partner during the interview process

6.6 Implications for Clinical Practice and Service Delivery

6.6.1 Is qualitative research useful in healthcare settings

According to Woods (1998), qualitative research methodologies are becoming increasingly important as 'tools' for exploring issues within health service research. In this respect, Brown (1998) argues that because reliably generalising aggregated group

data to an individual is impossible findings of qualitative research may be more useful, than some quantitative research. Research, therefore, which suggests more individual 'solutions' is most appropriate for clinicians and for the facilitation of good 'research-practice' links.

6.6.2 *Service delivery to people with fertility problems*

(i) Clinical Psychology services

Within the survey, contact by Clinical Psychologists with male clients was rare in comparison to contact with women. It is possible that this gender distribution accurately reflects the different psychological needs of infertile men and women. However, whilst Woollett (1992) has argued that the impact of infertility on women's lives and identity is greater than for men, therefore, female clients have greater clinical needs. The Researcher suggests, that because female clients are consistently found to be over-represented in mental health services (HMSO, 1987), it is more likely that gender inequalities exist in terms of access to Clinical Psychology services.

Two reasons are suggested to account for this poor uptake of services by men. First, because men are likely to be influenced by the pervasive social message that infertile men are less than 'real men', accessing services, and thus 'publicly' recognising infertility may be too difficult. Second, both referrers and men themselves, may perceive that women's needs are paramount, given the largely female context within which infertility is located (for example, a large proportion of Clinical Psychologists working with people with fertility problems do so under the umbrella of "women's services").

The following are suggestions for how Clinical Psychology services can be made more accessible to potential male clients. One way would be to encourage more male therapists to undertake work in this area, and to offer male therapy groups, through which men could gain support from like others, and explore fertility issues within a male context. Similarly, more preventative strategies would be to promote general issues of men's physical and mental health, perhaps through consultancy work with well-men clinics (or where these do not exist, developing such services).

In addition to this, Clinical Psychologists working in adult specialisms need to consider how they 'advertise' their therapeutic services to the infertile population as a whole, and to potential referrers of this population. The way in which the current system operates suggests that some individuals with fertility problems need to become symptomatic in order to access therapeutic services. Pathologising individuals in this way is clearly not helpful. Whilst the social climate may be changing, sexual issues becoming easier to discuss, Clinical Psychologists do have a role to play in educating and informing others of the acceptability of accessing therapy services for problems such as infertility.

(ii) Infertility services

The first NHS clinic approached by the Researcher, stated that they would be unable to access individuals who had discontinued IVF treatment (the sample required for section two of the investigation). This highlights that this group of clients are a largely 'unknown quantity' to those working in infertility services, and that professionals in these services, as elsewhere, have little knowledge about what happens to individuals stopping treatment once they have left services. Whilst the current survey findings

suggest that these individuals are unlikely to present to Clinical Psychology services, the qualitative experiences of individuals ending treatment, and leaving infertility services indicated that more therapeutic input is desired by this group to help them manage following the termination of treatment.

These findings suggest several recommendations that can be made to infertility services. First, it is important to recognise that stopping treatment will be an inevitability for a large proportion of patients, and that any measures that the clinic could take to help couples feel more in control during the IVF process would be greatly welcomed. Therefore, incorporating more pro-active, preparatory work within the clinic counselling model may improve outcome for those ending treatment in the future. For example, couples may find that devising a 'counselling plan or contract' which prepares them for treatment ending at an early stage within the process, or one which encourages them to plan, from the outset, the number of cycles they will undertake, will enhance service users sense of control, involvement and predictability and thus make adjustment easier if, or when, unsuccessful treatment has to end.

Second, the process of adjustment and coping will be made more difficult if individuals are told to stop treatment by the clinic. Breaking 'bad news' is always painful for both the bearer and the recipient, however, dissatisfaction with this type of process is not inevitable (Charlton, 1992). It is suggested that individuals told to stop treatment would benefit from a more formalised discharge plan with the clinic. This could take the form of either 'follow up' telephone or face-to-face contacts with the 'news-giver' and/or clinic counsellor, and would aim to reduce individuals' feelings of abandonment and loss, and thus make it easier for them to accept the decision and move on.

The third area of service need which seems to emerge from the qualitative interviews, is in relation to individuals who had secondary infertility (that is those who already have a child). This group perceives current service provision as inappropriate for their specific needs. From a mental health perspective one must consider the affect that parents' poor adjustment and coping following IVF treatment termination, will have on the child already born. Whilst the Researcher is not suggesting that the needs of this group are greater than those of others stopping treatment, services may need to modify their conceptual view of the experience of this group. Simply regarding secondary infertility as a psychologically 'protective factor' is not useful for the families concerned, and perhaps different service initiatives may need to be devised to meet this groups' differing needs. For example, support groups specifically for those with secondary infertility.

6.6.3 *Therapeutic issues for Clinical Psychologist*

Utilising the proposed theoretical framework which has been developed within the current study (explaining the experience of those adjusting to IVF treatment termination), Clinical Psychology intervention with individuals who have discontinued infertility treatment would be feasible at any one point along the *continuum of adjustment*.

Depending on clinicians formulation of their clients' problems, therapeutic tasks could include: (1) cognitive restructuring, that is shifting the client's locus of control from external to internal, or employing strategies to enhance clients' feelings of self efficacy in other areas of their lives; (2) undertaking educational interventions, in which clinicians can actively inform clients about strategies for coping, and encourage

problem solving in order to facilitate the process of moving on; (3) interventions which address the client's belief system and allows them to ventilate feelings whilst challenging the unhelpful meanings attributed to their infertility beliefs.

A role also presents itself for Clinical Psychologists in terms of more systemic type interventions. These could include offering consultancy to infertility clinics and voluntary agencies who have contact with this client group (including adoption services), providing the psychological knowledge base to encourage more pro-active ways of working and to promote well-being for these clients.

Clinical Psychologists need also to be aware that advances are occurring all the time within the reproductive technologies. With developments in new treatments and refinements to those already in operation, the number of couples receiving treatment is likely to increase and inevitably the 'failure' rate, and the numbers stopping treatment may also rise. Therefore, the need for therapeutic services for this population may become more acute.

6.7 Areas for future Research

The reader is reminded that research in this area is at preliminary stage and the current study was intended, partially to serve, as a pilot for future research with this population. To develop this research, further theoretically driven sampling is required to test and, explore the emerging theoretical framework proposed to explain the experience of individuals discontinuing IVF treatment. Additionally, a search for 'negative' cases, which may not fit the framework should be undertaken. For example, are the factors identified in the current study relevant to individuals who

discontinued treatment more than a year ago? (i.e. those further along the 'acceptance line'). Whilst receiving treatment in itself may promote a resolution for some, can individuals ever be said to fully adjust to their childless status?

One other area of research which arises from the current investigation concerns Clinical Psychologists therapeutic work with this client group and in particular what such therapy involves. Whilst the current research has begun to explore the different therapeutic tasks that are identified by clinicians when working with people with fertility problems, it may also be useful to explore the specific content of this work and perhaps the psychological models favoured by clinicians. Furthermore, discovering the level of client satisfaction with services may also extend understanding in this area.

6.8 Conclusion

The current investigation has enabled a theoretical framework to be developed around the experience of individuals discontinuing IVF treatment and their adjustment and coping following this process. Various psychological and social factors have been identified as having the potential to lead to a greater or lesser degree of adaptation, with the effects of these factors mediated by the individual's own system of beliefs. This model, however, can only be tentatively accepted, and further research is required to confirm or extend the hypotheses developed.

The current investigation has also highlighted the role played by Clinical Psychologists who deliver services to this client group. It is suggested that at present, services may not be fully addressing the therapeutic needs of this population, and that particular difficulties may exist at the point of initial referral.

Overall, these findings have important implications for clinical practice and for the way in which services for the infertile are planned and organised. It is hoped that in some way, through highlighting the largely unexplored psychological needs and experiences of this client group, this will have a positive impact on the well-being of these individuals in the future.

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Appendices

Appendix One

- 1. Letter to Chair of Salomons Ethics Committee**
- 2. Response - full ethical approval obtained**

Flat 4
108 Ravensbourne Avenue
Shortlands
Bromley
Kent
BR2 0AX

15th March 1998

Dr Tony Lavender
Chair - Salomons Ethics Committee
Salomons Centre
Broomhill Road
Southborough

Dear Dr Lavender

Re: Infertility: therapeutic contact with clinical psychologists and psychological well-being following failed In Vitro Fertilisation and decisions to discontinue treatment - A quantitative and qualitative analysis.

I am writing to request Ethical approval for the quantitative section of the above research project. The qualitative part of the project, because I intend to access a clinical population, is currently being scrutinised for ethical approval by

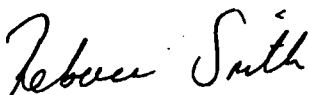
Research Ethics Committee. I have enclosed details pertaining to the full project for your information and to assist the committee in making it's decision.

Please find enclosed the complete research proposal, and copies of the survey sheet, information leaflet, participant consent form and interview topic guide which I intend to use .

I would like to request, because of the time constraints on this project, that any changes the committee considers necessary once made, would be subject only to Chair approval.

I look forward to hearing from you at your earliest convenience.

Yours sincerely



Rebecca Smith
Psychologist in Clinical Training

Salomons Centre
David Salomons Estate
Broomhill Road, Southborough
TUNBRIDGE WELLS
Kent TN3 0TG

Telephone: 01892 515152
Facsimile: 01892 539102

Our Ref: LT/075
Direct Fax: 01892 518446
E-mail: l.thompson@salomons.org.uk



SALOMONS
CENTRE

Ms R Smith
Flat 4
108 Ravensbourne Avenue
Shortlands
Bromley
Kent BR2 0AX

25th March 1998

Dear Rebecca,

Re: Ethics Approval – Infertility: therapeutic contact with clinical psychologists and psychological well-being following failed In Vitro Fertilisation and decision to discontinue treatment – A quantitative and qualitative analysis.

The Ethics Panel is pleased to provide full ethical approval for your research project. The Panel were impressed with the thoroughness of the proposal and the way in which the ethical issues had been considered and taken into account.

We wish you well with the project and would be extremely interested to see the results.

Yours sincerely,

Dr A Lavender
Chair
Ethics Committee

Subfertility: frequency of contact with therapeutic services - A survey

The aim of this study is to explore how frequently individuals and couples present for psychology services with issues related to problems of fertility, failed fertility treatment and decisions to stop fertility treatment. If you are currently, or have in the past worked in a therapeutic setting, I would be grateful if could complete this brief questionnaire.

Please state the client group(s) that you work(ed) with

1. Have you ever worked therapeutically with individuals or couples who have had fertility problems?
☐ Yes ☐ No

If no, please now return the questionnaire in the pre-paid envelope (this information is a vital part of the data set). If yes, please continue.

2. Please indicate whether the clients you refer to above (tick all that apply)

- ☐1 were having fertility treatment during therapy with you
☐2 had successful fertility treatment (i.e. child born)
☐3 had unsuccessful fertility treatment in the past & intending to try again
☐4 had unsuccessful fertility treatment in the past & a decision to stop treatment was made
☐5 had no fertility treatment, ever, as far as you are aware
☐6 had no fertility treatment, but intending to in the future

The boxes above are numbered; please indicate (approx.) how many people you have seen in each category

	Men	Women	Couples		Men	Women	Couples
1	4
2	5
3	6

3. Which of the following reasons were the above clients' referrals related to: (please number the boxes 1-4, where 1 is the referral reason that in your experience has been most common, through to 4 as the least common)

- i) their fertility problems ☐ ii) unsuccessful treatment ☐
 iii) decision to stop treatment ☐ iv) unrelated to fertility ☐

4. Did you identify one of the tasks of therapy for any of the above clients as: (please number the boxes 1-4, where 1 indicates the issue most commonly identified as a therapeutic task, through to 4 as the least common)

- i) coping with infertility ☐ ii) adjustment following decision to stop treatment ☐
 iii) coping with unsuccessful treatment ☐ iv) infertility not a task for therapy ☐

5. Did you have a sense that your clients had resolved these fertility issues by the end of therapy?

- ☐ Always ☐ Quite Often ☐ Sometimes ☐ Rarely ☐ Never

Please use the back of this page for any additional comments you wish to make.
 Thank you for your time. Please return in the enclosed pre-paid envelope.

If you have taken part in this study & wish to have a copy of the results please write for a short report to:

Rebecca Smith
 Clinical Psychology Training Scheme
 Salomons Centre
 Broomhill Rd
 Southborough
 Tunbridge Wells, TN3 0TG

Appendix Three

- 1. Initial letter to Ethics Committee Chair**
- 2. Response - decision pending one minor change to information sheet**
- 3. Second letter to Ethics Committee Chair**
- 4. Response - full ethical approval obtained**

11th March 1998

Dr

Dear Dr

Re: A qualitative study investigating the psychological adjustment and coping of men and women following failed In Vitro Fertilisation (IVF) and their decision to discontinue treatment

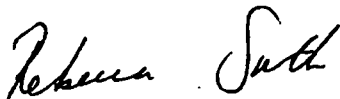
I am writing to request Ethical approval for the above research project which I am conducting as part of my Clinical Psychology Doctorate (South Thames Clinical Psychology Training Scheme). The project is being supervised by Dr Margie Callanan, who is the Research Director of the South Thames (Salomons) Clinical Psychology Training Scheme. In addition to this, Consultant Assisted Conception Unit, has expressed a willingness to support the recruitment of participants for the research.

I have enclosed the required number of copies of the Research Ethics Committee Protocol Pro-forma, and copies of the information leaflet, participant consent form and interview topic guide which I intend to use.

I would like to request, because of the time constraints on this project, that any changes the committee considers necessary once made, would be subject only to Chair approval.

I look forward to hearing from you at your earliest convenience.

Yours sincerely



Rebecca Smith
Psychologist in Clinical Training

25 March 1998

Ms R Smith
Salomons Centre
David Salomons Estate
Broomhill Road
Southborough
Tunbridge Wells
Kent

Dear Ms Smith

Re: Protocol Number: 1998-0097

A qualitative study investigating and coping of men and women following failed In Vitro Fertilisation (IVF) and their decision to discontinue treatment.

At the recent meeting of the Research Ethics Committee on Wednesday 25 March 1998 your submission was reviewed. The Committee regrets that the decision awaited on your submission is still pending, subject to the following information being provided.

Notes:

The committee insists that the Patient Information Sheet clearly mentions that participation in the study is entirely voluntary and that refusal to participate in the study, or withdrawal from the study would not affect the patients future care or treatment in any way.

Yours sincerely


**Chair of Research Ethics Committee
Healthcare NHS Trust**

cc Mr , Assisted Conception Unit

4th April 1998

Dr

Dear Dr

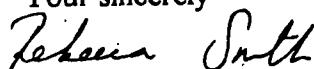
Re: A qualitative study investigating the psychological adjustment and coping of men and women following failed In Vitro Fertilisation (IVF) and their decision to discontinue treatment

Please find enclosed the information leaflet for the above research project which I have made the required addition to.

I hope that this meets with your full approval and that I may now proceed with the project.

Thank you for your help with this matter

Your sincerely



Rebecca Smith
Psychologist in Clinical Training

21 April 1998

Rebecca Smith
Salomans Centre
David Salomans Estate
Broomhill Road
Southborough
Tunbridge Wells
Kent
TN3 0TG

Dear Ms Smith

Re: Protocol Number: 1998-0097

A qualitative study investigating the psychological adjustment and coping of men and women following failed In Vitro Fertilisation (IVF) and their decision to discontinue treatment.

Thank you for providing a copy of the Patient Information Sheet incorporating the changes as requested by the Research Ethics Committee. I am pleased to confirm that the above study now has full ethical approval.

Yours sincerely



**Dr
Chairman
Research Ethics Committee**

cc Mr

Dear Mr and Mrs

I am seeking to recruit volunteers to take part in a small project being carried out in association with the Assisted Conception Unit at , looking at how the decision to end IVF treatment effects peoples' lives and their psychological well-being.

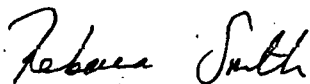
I am very interested in talking to people like yourselves who have been through the difficult, and often distressing process of ending treatment. Whilst I fully appreciate that revisiting this time in your life may be difficult, I would be extremely grateful if you would consider taking some time to share your experiences with me, and thus help us to learn more about what helps and hinders peoples' adjustment and coping at this time.

I have enclosed with this letter an information leaflet which states more comprehensively the details of the project, along with a tear off section (and sae) for completion if you would like more information or would like to participate.

May I thank you for taking the trouble to read this letter, and I very much look forward to hearing from you in the future.

Best wishes

Your sincerely



Rebecca Smith
Psychologist in Clinical Training

Information Leaflet

A study investigating the psychological adjustment and coping of men and women following unsuccessful In Vitro Fertilisation and their decision to discontinue treatment

A project is currently being carried out in association with the Assisted Conception Unit at looking at how the decision to end IVF treatment affects peoples' lives and their psychological well-being.

It is widely recognised that receiving treatment for infertility is a highly stressful process. In some cases treatment is unsuccessful and the decision to stop has to be made. This can be a distressing time, and the process of coping and adjusting following this decision can be long and hard. Whilst individuals cope in their unique ways, some do seem to find it easier than others. Generally however, all people faced with this situation appear very resourceful and resilient.

The aim of this research project is to learn from the experience of people who have been through this difficult process, focusing in particular on what they believe helped and hindered them along the way. By identifying these factors, it's hoped that people making this same decision in the future can be assisted to cope as well as possible.

The researcher would like to talk to men and women who following unsuccessful IVF treatment decided to, or were recommended to, discontinue with treatment.

Taking part in this study would involve giving between 1 and 2 hours of your time to be interviewed by the researcher, at a time and place that is convenient to you. During this interview you would be asked to talk about your experience of the IVF process and about how things have been for you since you decided to end treatment. Your consent would be asked to tape record the interview. You are assured of confidentiality. A short report of the outcome of the study would be offered to each individual participating - individual participants would not be named in this report.

Taking part in the study is entirely voluntary. Refusal or withdrawal from the study at any stage will in no way affect your future care or treatment.

If you would like more information about the project or are interested in taking part please complete the tear off slip and return in the enclosed sae. Thank you for your time.

**Rebecca Smith (Psychologist in Clinical Training)
Contact ☎ (01892) 515152**

I/we are willing to be contacted by the researcher, Rebecca Smith, in order to discuss the project & participation more fully. If during this telephone call I/we decide that I/we would like to participate I/we would be happy to then arrange a meeting.

Name(s)

Address

.....

Tel No **(Best time to phone**

Signed **Date**

Signed **Date**

Topic Guide for Semi-Structured Interview

Introduction

Information Leaflet - have participants read and understood all requirements/details?
Consent (form - signing and witnessing, audio tape recording)
Questions - participants any questions before begin?

Demographics

Participants age(s), occupation(s), family composition ...

Experience of the IVF process

Other kinds of treatment/intervention prior to IVF process?
Details of treatment cycle(s) Reasons for pursuing - pressures? feelings?
What was experience of undergoing IVF like? (& for partner?)
Support during - how supportive were those around - family, professionals

The decision

Decision making - how was decision reached? Impact? Who was involved in process?
Evaluation - do they think it could have been done better/differently? In what way(s)?
Counselling - to help make decision? Once decision made? Offered vs taken up?
Emotional impact - what were feelings once decision made? - Different to feelings previously (did partner feel similarly? different?) - feelings now?
Do they believe it to be final decision?

'Post decision'

Since stopping treatment how, if at all, has life changed?
'Difficultness'
Support received? - family, professionals
Style of coping - problem vs emotion focused
Construction of alternative future(s) for self - acceptance of 'childlessness' - explored other options i.e. adoption
Others reactions/responses? Do others look at you differently? Stigma?

Debriefing

Thanks for - taking part, sharing experiences/memories which it may have been difficult/distressing to do at times during interview
Any further things thought would say/would have liked to have said?
Questions? Check participants feelings now?
Information re what happens now - report, extra support, tape
Provide information on local support services, counselling within unit if necessary

Other/Notes

HEALTHCARE CONSENT FORM

A qualitative study investigating the psychological adjustment and coping of men and women following failed In Vitro Fertilisation (IVF) and their decision to discontinue treatment

Date approved by Ethical Committee: 21st April 1998

No: 1998-0097

I (name)

of (address)

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I am to be assured of strict confidentiality and that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so.

I do/do not* consent to the interview being tape recorded.

I would/would* not like to retain the recording of my interview once it has been transcribed.

(*delete as appropriate)

SIGNED (Volunteer) Date

Researcher Date

2 copies required: one for researcher, one for volunteer

Inter-rater reliability study

Instructions for rater

The aim of this study is to determine to what extent an independent rater concurs with the codes and categories I have generated from the responses given by participants.

I have provided you with two interviews (labelled A & B), randomly selected from the sample interviewed, two copies of the 'category' rating scale, and copies of the 'codes' rating scale.

To begin with I would like you to take interview A and one of the 'category' ratings scales. Please read the interview through carefully. As you do so I would like you to think about what the participants say about their experience of stopping IVF treatment and what they say about their lives following this decision. Please then read the interview again this time ticking one or more of the category boxes whenever you feel that the participants have made a comment that fits this category. Each box can only be ticked once for each person no matter how many times they mention this issue.

Could you then take one of the 'codes' rating scales. Again I would like you to repeat the procedure this time ticking off the boxes on the 'coding' scale. (Please indicate whether this has been said by the male or female participant). As you will see these are more specific comments or descriptions and sometimes participants comments will not fit any of the codes mentioned.

If at any stage throughout this process you feel that participants have made comments which you feel are particularly pertinent to the area of stopping IVF treatment, but have not been included on either of the ratings scales please note this down at the bottom of the relevant interview rating scales.

Please now repeat all the above for interview B.

Thank you for your help.

'Codes' Rating Scale

	m	f
adoption not an option because already have a child	[]	[]
others don't understand	[]	[]
finances forcing decision to stop	[]	[]
helped not knowing with whom the fertility problem lies	[]	[]
coped by throwing self into other activities	[]	[]
feeling that there's more to life than children	[]	[]
having a philosophical approach to life	[]	[]
insensitivity of people saying 'well at least you've got one'	[]	[]
felt afraid that others would disapprove of IVF attempt	[]	[]
since said no more felt calmer and more relaxed	[]	[]
not ready to give up trying	[]	[]
accessed counselling through GP	[]	[]
talking to others in similar situation would help the 'healing process'	[]	[]
feeling as though she has cheated her son	[]	[]
blames self	[]	[]
feeling isolated	[]	[]
felt neglected by the clinic	[]	[]
talking has been the most helpful	[]	[]
continually thinking about having another child	[]	[]
feeling jealous of other women	[]	[]
'difficultness' of having the decision to stop enforced upon you	[]	[]
needing to feel that they had given treatment their 'best shot'	[]	[]
husband disagreed with IVF	[]	[]
Finds it harder to cope because the fertility problem lies with her	[]	[]
relief when treatment ends	[]	[]
using the adoption process to help manage the IVF disappointment	[]	[]
learning about yourself through the IVF experience	[]	[]
just as much chance of conceiving normally as with IVF	[]	[]
importance of final appointment with clinic	[]	[]
life plan was to include children	[]	[]

hard to get over the loss

[] []

feeling dis-empowered by the adoption process

[] []

choosing to forget about the IVF experience

[] []

feeling that it wasn't the best time to try because I had a cough &
temperature

[] []

'Category' Rating Scale

Taking control yourself of the situation	[]
Feeling that life on hold during IVF	[]
Positively re-framing life without children	[]
Adoption (negative aspects)	[]
'Unexplained' infertility as a negative factor	[]
Not informing others of treatment (positive)	[]
The importance of communication with partner	[]
Positive feelings once treatment ended	[]
Sharing experiences with others	[]
Ways of coping	[]
General area in which support was lacking	[]
'Unexplained' infertility as a positive factor	[]
Feeling unsupported by partner	[]
Expectations (unhelpful)	[]
The continued hope for natural conception	[]
General factors which made it easier to stop	[]
attributing external causes to treatment failure	[]
Helpfulness of being prepared for ending at the beginning of treatment	[]
Unhelpful aspects of friendships	[]
Using formal services for support	[]

Dissertation Diary

Research wk

June '97

Searching for an idea, want to find something to look at that I'm really interested in - oh help?

Topic of infertility came up in conversation with someone, started me thinking about the whole infertility treatment process - what are the decisions that couples have to make?

Began reading around the topic of infertility & IVF, surprised by the poor success rate of IVF treatment. Got to thinking about the process of stopping treatment and how this might affect couples. How do couples manage the decision to stop IVF treatment? Do the same factors drive many couples to continue? Is it a decision made for them by professionals?

3rd July '97

Literature searches show that no research has been done looking at couples who have had failed treatment and then stopped. There must be a group of people for whom this is an issue. How are they coping? Are they presenting to Clinical Psychology services with difficulties following this experience? Are there risk/predicting factors for successful coping?

Consider how relevant this would be to clinical practice - could I identify clues to help future couples, identify those at increased risk?

Margie Callanan agrees to supervise the research. Discuss possible research methodologies with Margie. Borrow book on qualitative methods to find out more.

Discuss potential difficulties re recruiting participants. Decide that I need to try and talk with IVF consultants to see if they would be willing to support the research & recruitment of participants through their clinics. Need to find out how feasible recruitment would be - how many couples do they see each month who have made or are told to make the decision to discontinue with treatment?

10th July '97

Decide to write to Dr Robert Edelmann (individual who has done lots of research in the area of infertility) to see if I could meet with him to discuss my ideas

15th July '97

Discussion in supervision re qualitative vs. quantitative methodologies. Is it enough to state that the rationale for using qualitative methodology is because it will be less distressing, less impersonal for couples? Need to read more!

Met with Dr Edelmann. Took ages to get to him at Surrey University but well worth it. Feel more confident now that this area valuable one to research. He suggested some useful references to look up and gave me a copy of his two most recent (in press) articles.

- 17th July '97** Writing research proposal. After much deliberation decide to use grounded theory approach as new area of enquiry and will enable me to develop theoretical understanding of the issues.
Decide that will need some research questions (although not usual in grounded theory) to inform my interview schedule and to gain ethical approval
- Aug/Sept '97** Submit my research proposal and await outcome. Begin to think about designing interviews and ways to recruit participants
- 2nd Oct '97** Receive approved from board of examiners today with no changes. Draft outline of semi-structured interview, consider ethical issues re support for participants and level of distress - what strategies could I put in place to minimise distress?
- 28th Oct '97** Discussed proposal with Laura Tomlinson (placement supervisor), she suggests approaching Clinical Director of women's services & Prof. of Assisted Conception Unit at hospital re recruitment of participants. Laura writes on my behalf.
- 13th Nov '97** No news from above people - is no news good news?! Complete hospital ethics form - is there any point submitting this if the unit won't support research?
Exploring other avenues for recruitment - Margie agrees to speak with fertility counsellor colleague at another hospital (Marjorie Rutter).
Topic guide for interview schedule drafted.
Am I wasting my time doing all this - what if I can't get any participants? Do I need to think about changing my tact. I don't want to think about stopping - invested so much time and emotion in this, perhaps I can learn from this in terms of slight parallels with process/emotions my research participants are experiencing.
- 5th Dec '97** Still no news - both Laura & I have spent last few weeks chasing Drs - why are they so elusive? Begin to think that there's no research in this area because either participants don't exist or they're just too hard to get hold of.
- 12th Jan '98** IVF Prof. has eventually got back to me! He believes research would be worthwhile, although doesn't think will get useful results with such small sample - doesn't seem to understand qualitative research. All research in department is very medically oriented with large samples. Thinks that problem will be with recruitment, & in particularly deciding when participants have actually stopped treatment. Suggested speaking to researcher in dept & counsellors
- 26th Jan '98** Meet with unit researcher. Again she has concerns re getting participants - not unusual for couples to leave 6/12 months between treatment cycles, perhaps because they are saving up to try again. She

has concerns re sending out information sheets to patients when it is not totally clear that they have finished treatment, could just have gone to another hospital. IVF population apparently renowned for going from clinic to clinic. There is some hope though - she says there are people who she has advised to stop (and thinks that there will be other professionals in dept who have done same thing) could approach these.

Arranged meeting with unit's counsellor.

29th Jan '98 Meeting with counsellor. She doesn't think its do-able through their clinic. Apparently the clinic don't have contact with people who have decided to terminate treatment (what happens to them then?) Couples usually very angry if clinic advises them to stop and the last thing they want to do is have contact again with hospital, may go somewhere else for treatment or cope alone. Couples rarely return to hospital for follow-up counselling appointment - why is this?

After long hard deliberation and discussion with Margie decide perhaps that its time I stopped!

Begin thinking about where might these people be who stop. Are they coping alone or do they receive help from somewhere to cope? Consider that it would be interesting to find out if these people access Clinical Psychology services. Explore literature and see that nothing is known at all about Clinical Psychologists contact with people with fertility problems - maybe a survey of this contact would be useful.

Think also about finding out about the typical pathway for individuals terminating treatment, through interviews with fertility counsellors. How do people progress following failed fertility treatment and how do they finish? What percentage (nos.) drift away from services and what percentage actually decide? What percentage don't come back? What percentage get closure? How many follow-up appointments are offered? Where is closure happening? Where are people dealing with endings?

Decide upon central research questions as follows - Where are these people? What happens to them? How are they feeling? How are they managing?

Make changes to research proposal to re-submit. Add statement about feasibility. Counsellors at hospital agree to be interviewed.

30th Jan '98 Wrote to Chair DCP with copy to editor of Forum re possibility of sending out survey with forum.

Feb '98 Design survey instrument & pilot.
Found out about BPS direct mailing service and receive quote for sending out 1000 questionnaires to random sample of Division of

Clinical Psychology. The course have thankfully agreed to meet this cost which will save me considerable time (which is very precious now).

Completed another hospital ethics form re approval to interview clinic counsellors and submit.

Out of the blue receive a telephone call from Marjorie Rutter. She and the consultant (Mr John Parsons) at the hospital she works at are interested in supporting my original proposal! Arrange to meet her next week. Not sure whether this is the right thing to do - should I just stick to my decision to give up. This is really difficult.

26th Feb '98 Discuss in supervision meeting with Marjorie Rutter. Margie says to go and see what Marjorie says about getting a sample.

2nd Mar '98 Met with Marjorie Rutter and Mr Parsons today, both v. helpful. She feels that the original project is v. do-able. Believes that I could get a sample at their hospital.

Decision time - I really want to go with my original idea. I feel that the findings from this would be more worthwhile, learning about the experience of those individuals themselves rather than the counsellors perceptions.

I've made a decision! I've decided to go with interviewing patients & to continue with survey as well as I believe it to be extremely valuable to know whether individuals with fertility problems are accessing Clinical Psychology services.

Ethics approval received from 1st hospital re interviewing counsellors - this is not needed now, must write to chair to inform her of this.

Submit proposal to Salomons ethics committee for permission to do survey and submit to 2nd hospital ethics committee re qualitative interviews. If I have to fill in another ethics form I might scream!

25th Mar '98 Ethics approval received today from Salomons. Spent my weekend photocopying 1000 survey sheets and sticking 1000 sticky labels onto envelopes. Sent all this to the BPS for distribution. Now all I have to do is wait!

Ethics approval from 2nd hospital subject to one minor change to information sheet. It really feels that things are at last coming together - is it all happening too late though!

9th & 16th Apr Trawled through files at Assisted Conception Unit. Identified 24 couples who fit my research criteria and send letters & information sheets sent out - more waiting now.

Questionnaires have begun to flood in, nearly 200. Plan data base with Margie, set up and started putting in data.

20th Apr '98 One couple have replied and have agreed to be interviewed next week. Brilliant news but I hope more people reply soon. Another 100 or so questionnaires returned.

23rd Apr '98 Decided with Margie that I need to send out more letters and information sheets. Sent out another 8 which I already had addresses for but will need to go to hospital again next week to see if there are anymore.

Total no of questionnaires now received is 379. Margie says this is an excellent response.

27th - 30th Apr Another couple have replied and I'm going to interview them this week. By the end of the week I will have a sample of four. Practised with the recording equipment & went through the interview topic guide to check that nothing is missing - beginning to feel a bit anxious.

Sent out more information leaflets & letters to potential participants, Marjorie send some out as well.

Start to think about the write up - plan introduction.

I've interviewed two couples now. I had underestimated the emotional energy that this was going to take. Listening to people's stories is quite draining and completely different as researcher not therapist. The first couple seemed very supportive & had obviously talked at length to each other. It seems striking the lack of support people have received and the reliance they have had to place on their own coping resources.

I experienced the second couple very differently from the first. Here, the female partner seemed somewhat unreal and often defensive in her remarks. I didn't feel that I warmed to them as much, but they did perceive themselves to be coping fine and perhaps who am I to question this?

Began transcribing - this is going to take hours (& I'm getting leg cramp from the transcribing machine foot pedal). Each interview is taking between 7/8 hours to transcribe - help!

12th/14th May Just finished two more interviews, total sample now of 8. It all feels a little overwhelming. My admiration for these people is growing by the day.

Found listening to couple three extremely distressing. They had been told to stop treatment and this was obviously very painful for them. I think though, being interviewed did help them in some way.

Couple four were the first couple interviewed with secondary infertility - got me thinking about how different this is to the experiences of those with primary infertility. Experienced the female partner here as cold & hostile and attacking towards her husband. She was unsympathetic to his distress and almost seemed irritated by his accessing of counselling services, which she perceived as a reflection of his inability to cope.

Wrote the methodology section & completed analysis for the quantitative section, total response was 436.

Margie has given me the NUD-IST computer programme to help with the organisation of my transcripts but it seems too difficult to understand. Decide that time trying to work out how to use the programme would be time better spent on transcribing and write up.

- 21st May '98** Interviewed my ninth participant today. A female participant whose partner didn't want to take part. This was the first participant where the origin of the infertility was known - wonder whether this effects the process in some way? - issues of blame and fault emerged. This women seemed particularly unsupported by her family and partner.
- 27th May '98** Interviewed the final couple this evening. They had a very interesting story to tell about their 'trials' with the adoption process - this seems as traumatic as IVF itself. Aren't these couples resilient!
- 30th/31st May** Finished all the transcribing this weekend! Now to get totally 'immersed' in the data! Begin reading and re-reading.
- 6th/7th June** First draft of the introduction completed, sent along with method and quantitative results to Margie for comments. Feeling pretty exhausted.
- 12th June '98** Supervision with Margie. Useful discussion about how to link both sections of the project together better. Decided upon a title - needed to get it brief enough to fit on the spine once bound. Bound am I ever going to get to that stage!
- 13th June '98** Take a step back and think about all my experiences of the interviews before going any further with the analysis.
- 14th June '98** Begin with the first transcript and read and re-read starting to identify basic codes.
- 18th June '98** Have been off all week on study leave & have spent all my time coding interviews, have identified 254 basic codes. The process was much more difficult than I had anticipated, had to keep checking myself that I wasn't imposing my own ideas onto the data and categorising too soon.

Discussed the codes & the next stage of the analysis with Margie in supervision and will now spend the weekend developing conceptual categories!

- 20th/21st June** Worked all weekend to develop the conceptual categories. Completed inter-rater reliability and thankfully the agreement was good.
- 25th June '98** Began writing up the qualitative results this week (will have to condense a lot of the material as space limited), & thinking about the thematic analysis which I discussed with Margie today. Feel under considerable pressure for time - beginning to panic about finishing.
- 2nd July '98** Met with Margie again today - she gave me confidence that I can do it! Write-up complete up to discussion (just about). Panicking about developing a theoretical framework for my data - Margie helped me to be realistic about this (I don't have to be another A.T.Beck!). Seems helpful to present a flow diagram of the pathway individuals take following treatment termination and a diagrammatical representation of the interplay between the factors of adjustment.
- 10th July '98** Writing the discussion and finishing off other bits and pieces this week. Been to the course today - feels quite anxiety provoking seeing where everybody else is at! Feedback received from Sue Holtam re results section, v. helpful she even said that she had found it interesting reading!
- 12th July '98** Final full draft to Margie awaiting comments - hope they'll be time to change things if necessary before submission on Friday.

Conceptual Categories

The categories generated are underlined, with the codes subsumed within each category presented below it. The number in brackets following each code indicates the number of male or female participants who gave a response which could be included in this code.

Area One - The Experience of IVF

1. Not informing others of treatment - positive

not telling others about treatment attempts helps one to cope with disappointment (2f,2m)

2. Not informing others of treatment - negative

feeling that perhaps not telling others was selfish and minimised support to be gained (f1)

feel as though leading a 'double life' (f1)

keeping it a secret meant we only had each other (f1,m1)

3. Reasons for informing others

telling people so they don't have to tread carefully (f2)

it hurts more when people don't want to talk about things in front of you (f1)

it's easier to handle if you're open with people (f1)

4. Reasons for not informing others

feeling that didn't want everybody to know (f2,m1)

keeping experience quiet so as not to worry others (m2)

couldn't face telling others about treatment (f1)

uncomfortable because so personal (f1)

felt afraid that others would disapprove (f1,m1)

5. Feeling that life on hold during IVF

become the focus of their life (m1)

feelings as though life on hold with IVF (m1)

regret for missed opportunities during IVF (f1,m1)

6. Expectations - helpful

'down shifting' expectations to avoid disappointments (m2)

praise for the clinic for not raising false expectations (m1)

pessimism about treatment outcome (f1)

treatment not as horrific as expected (f1)
being realistic about chance of treatment success (f1,m3)

7. Expectations - unhelpful

expectations of treatment success increased as no. of cycles increased (m2)
Feeling optimistic about the IVF (f1)
having hopes built up by health professionals (f5,m1)
unit making it seem as easy as 'going out and catching a train' (f1)

8. Ambivalence

feeling frightened and avoiding treatment initially (f5)

9. The negative effect of information

negative impact of reading about infertility (f2)
denial of statistics when told (m1,f1)
wouldn't have taken any notice if someone tried to prepare me for disappointment (f1)

10. Lack of information - negative

Feeling emotionally unprepared (f2,m2)
more information would have been helpful (m1)
feeling uninformed (m1)
hard to know what questions to ask when you're emotionally tied up (f1)

11. General issues about information

using the media for information (f2)

12. Male partner feeling under pressure to 'perform' & be successful

producing a sample is a tremendous, almost unbearable pressure (m3)
pressure playing on your mind (m1)
pressurised partner to continue with treatment (f2)
wanting another go (f2)

13. Attributing external causes to the treatment failure

maybe my body just got a bit confused? (f1)
it wasn't the best time to try because I had a cough & temperature (f1)
you had the flu so it wasn't a good attempt (f1)
thought it might have made a difference if allowed to rest after egg transfer (f1)

14. Blaming self for treatment failure

seeing treatment failure as a personal failure (f2)
blaming oneself for treatment failure (f1)

15. Treatment failure disrupts 'life plans of family'

life plan was to include children (m1)
plan to have 2/3 children not accomplished (f1)
first experience of something in life going wrong (m3)

16. Negative feelings engendered by health professionals

negative experience of health professionals (f2)
treated as though they had an illness (f1,m1)
made to feel that we were a nuisance (f1)
not as special as we thought we were (m1)
aware that negative feelings only projection (m1)

17. Cautious responses of family members to treatment process

family surprised because no-one has ever had problems before (f1)
family wary of mechanical involvement (f1)

18. Financial stresses of treatment

having to pay for treatment (f2,m1)
getting little financial help because of cut-backs (f1)
pressure to continue with treatment because funded (f4)

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Area Two - The Decision to Stop Treatment

19. Taking control yourself of the situation

having a 'plan of action' to deal with the situation (f1)
making the decision at the beginning of treatment to only have 2 attempts (f2,m1)
feeling that they had given treatment their 'best shot' (f3,m1)
not wanting to have any regrets (f6,m2)
taking control of treatment rather than it controlling you (m1)
were able to 'put the IVF to bed' when felt done everything possible (m1)

20. The importance of communication with partner

communication within the relationship (f1)
agreeing with each other about treatment decision making helped (m2)
talking to each other alleviates friction (f1)
talking has been the most help (f1)
making time to talk to each other (f2)
not talking to each other can 'rip you apart' (f2)
only had each other ((f1,m1)
very open with each other (m2)

21. Feeling unsupported by partner

husband disagreed with IVF (f5)

22. Difficulties in communicating

found it difficult to talk to her husband when needed to (f2)
male partner finding it harder to talk (f1)
bottled feelings up for fear of hurting each other (f1)
Shutting each other out (f2)

23. Positive feelings once treatment has ended

felt relieved when treatment ends (f6,m1)
life returned to 'normal' (m1)
able to be concerned again with house, holidays & son's activities (f1)

strength of feeling diminishing as time goes by (f1)
since said no more felt calmer and relaxed (f4)

24. Negative feelings once treatment has ended

feelings of hopelessness (f3)
strength of feeling increased as no. of failed cycles increased (m1)
finding it hard to cope with normal life again (m1)
emotional 'ups & downs' (f1)
feelings of devastation when told to stop (f2)
disappointment (f3,m1)

25. Ways of coping

copied by throwing self into other activities (f1,m1)
trying not to ruminate on what might have been (f2)
copied by not talking about it (m1)
pretending that everything was all right (f1)
copied by retreating into self
needed to be alone
get on with other aspects of life (m2)
over time you become more resilient (f2)

26. Sadness

feeling sad that it hasn't worked (f3)

27. Loss

not knowing how to cope with the loss (f1,m1)
grieving (m1)
recognition of loss would have helped (f1)
when it doesn't work it's a death (m1)

28. Abandonment

felt abandoned by clinic (f2)
falling to pieces when contact with services stops (f2)
feeling as though we were forgotten (f2)
feeling as though you've fallen off the conveyer (m1)
felt neglected by the clinic (m2)

29. General areas in which support was lacking

feeling that it would have been nice to meet with other people and share experiences (f1)

not wanting to feel so alone (f2)
talking to others in a similar situation would help the 'healing process' (f1)
difficulties in managing IVF & other life events (m1,f1)
feeling that would have helped if someone professional to talk to (m1,f1)
crucial period after decision made when help is needed (m1)
would have liked some follow-up (f1)

30. Usefulness of formal services for support

gaining support from outside relationship (f2)
accessed counselling service through GP (f2,m1)
diagnosed with anxiety and depression (m1)

31. No need for formal support services

feeling that didn't need to make use of professional support (f1)
felt that didn't need to utilise support groups (f1)
felt uncomfortable with the public nature of support groups (m2)
private person (m2)

32. 'Unexplained' infertility as a positive factor

helped not knowing with whom the fertility problem lies (m2)

33. 'Unexplained' infertility as a negative factor

hard to move on because don't know what the problems is (m2)
nothing to focus on & to blame (m1)
need an explanation for why it didn't work (f2)
finding it difficult to give up hope because haven't been told it's impossible (m2)

34. Secondary infertility as a negative factor

harder to accept her infertility (f3)
felt as though she has cheated her son of a sibling (f1)
feeling as though son has been let down (f1)
felt unable to attend support groups for fear of offending others because already has a child (f1)

35. Secondary infertility as a protective factor

already having a child made it easier to cope (f1)
would have felt differently if didn't have son (f1)

36. Explained infertility as a negative factor

finds it harder to cope because the fertility problem lies with her (f1)
feeling angry with self because the fertility problem lies with her (f1)
blames self (f1)

37. Having different coping styles - neutral

different ways of coping within the relationship (f2)

38. Having different coping styles - positive

compliment each other - 'he's hopeful, I'm pessimistic' (f2)

39. Having different coping styles - negative

sometimes he's too hopeful (f1)

40. General negative aspects of having the decision to stop made for you

'difficultness' of having the decision to stop enforced upon you (f2)
couldn't have the decision made for us (f1)

41. Being told to stop - a barrier to moving on

couldn't give up had to seek a second opinion (f2)
needed to know that every avenue had been explored (m1)

42. Reaction to being told to stop

wanted to run away (m2)
needed someone to talk to but not the 'news-giver' (m1,f1)
wish that there had been some follow up (f1)

43. General factors which made adjustment to stopping easier

clinic offering hope of natural conception (f2)
importance of final appointment with clinic for 'closure' (m1)
realising that there was nothing else we could do (f2)
realising for self that it's time to stop (f1,m1)
realisation of one's own limitations (m1)
deciding for self (f1)

44. Stopping because of emotional strain

IVF not something you could just keep doing because it's so stressful (m2,f1)
feeling that IVF placed too much strain on relationship (f1)

45. Helpfulness of being prepared for ending at the beginning of treatment

being told from the outset that could only have 3 treatments helped (f2)
setting a limit from beginning on no. of treatment cycles (m2)

46. Finance driving the decision to stop

finances forced us to stop (f1,m1)

47. Importance of time for oneself

taking time off work (f2)
taking the time to do ordinary things again (f1)
holidays (f2,m1).
taking time for self reflection (f2)
going part-time at work (f2)
needed time to myself (f2)

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Area Three - Life Post-Decision

48. Positively re-framing life without children

feeling that there's more to life than children (m1,f3)
having a philosophical approach to life (m3)
feeling that we should be grateful for what we've got (f1,m1)
'Intellectualising' (m2)
look at the positive aspects of your life (m1)
think of all the things that you can do that others with children can't (m1,f1)
'things could be worse' (m1)
being together more important than having children (f1,m1)

49. Constructing an identity for self without children

being a mother isn't the only reason why I'm here (f3)

50. The continued hope of natural conception

just as much chance of conceiving normally as with IVF (f1)
continually thinking about having another child (f1)
not ready to give up trying (f2)
'in theory I should be able to get pregnant' (f1)
imagining life with another child (f1)
hanging onto the 'glimmer of hope' (f2,m1)
still believed that one day they would have a child of their own (m3)

51. Adoption - positive aspects

using the adoption process to help manage the disappointment of IVF (m2,f1)
adoption as 'therapy' (f1)
adoption giving something to focus on (f1)
adoption way of re-evaluating life and working out what we want (f1)

52. Adoption - negative aspects

feeling dis-empowered by the adoption process (f2)
feeling that adoption is more traumatic than IVF (m2,f2)
adoption almost as stressful as IVF (f1)

takes more energy than having own child (f1,m1)

53. Adoption - neutral

adoption not an option because have already conceived naturally (f2)
experience of friends who have been adopted negative (f1)
adoption isn't the cure for IVF (f1)

54. Views on egg/sperm donations

feeling uncomfortable with the idea of donor eggs/sperm (m1,f1)
felt that would be unable to cope with the long term consequences of it (m1)

55. Feeling resigned to one's lot in life

can't change it so just have to get on with life (m1)
feeling resigned to one's lot (f1,m1)

56. Sharing experiences with others

helpfulness of meeting with others in a similar position (m1,f1)
supportive talking to like others (f3)

57. Personal gains of IVF

learning about yourself through the IVF experience (m1)
gaining understanding and empathy through IVF (f1)
views have changed for the better about artificial conception (m1)
learning about your relationship through IVF (f2)

58. Positive responses of others

not being seen as 'lesser' or 'not complete' by others (f1,m1)

59. Negative responses of others

being made to feel isolated (f1)
others don't understand (f2,m2)
insensitivity of people saying 'well at least you've got one' (f3,m1)
others think I don't understand what it's like to be 'childless' because I have a child (f1)
others making thoughtless comments (f1,m1)
others having unrealistic expectations of treatment (m1)
pitying responses of others (f1,m2)

60. Feelings towards those with children

feeling that others should appreciate how lucky they are - 'being a parent is a privilege not a right' (m1)

feeling jealous of other women (f1)

avoiding contact with pregnant women and those with children (f1)

being uncomfortable around mums (f1)

61. The 'unjustness' of the world

feeling that life isn't fair (f1,m1)

62. The negative impact of society

finding life around children 'punishing' (f1)

feeling that there's no getting away from reminders of children (f1)

63. Receiving support from family

support from family (f2,m2)

feeling that family sensitive to plight (f2)

64. Importance of friendships

practical support from friends (f1)

good friends to talk to (f2)

65. Unhelpful aspects of friendships

friends say that I must be so brave (f1)

friends worry that we will feel left out (m1)

friends putting pressure on us to try again (m1,f2)

people always want to offer a solution (f2)

66. Availability of technology makes adjustment difficult

feeling that would have come to terms with situation earlier but treatment offers hope (f1)

67. Current triggers to distress

remembering dates of failed attempts (f1)

births in the family bring it all home again (f1)